

REPORT from  
A National Consensus Development Conference

# Caregiver Assessment: Voices AND Views

FROM THE **Field**

VOLUME II



APRIL 2006



FAMILY CAREGIVER ALLIANCE®  
National Center on Caregiving



## About Family Caregiver Alliance

Founded in 1977, Family Caregiver Alliance serves as a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy.

Long recognized as a pioneer among caregiver organizations, FCA operates programs at local, state and national levels. FCA is the lead agency and model for California's statewide system of Caregiver Resource Centers. In 2001, FCA established the National Center on Caregiving to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country. Visit [www.caregiver.org](http://www.caregiver.org).

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# Foreword

The National Consensus Development Conference *for Caregiver Assessment* brought together 54 invited experts to advance policy and practice on behalf of family and informal caregivers. The conference, convened by the National Center on Caregiving at Family Caregiver Alliance (FCA) on September 7-9, 2005 in San Francisco, had two goals: (1) to generate principles and guidelines for caregiver assessment; and (2) to build common ground among leaders committed to innovation, experimentation and the systematic generation of new knowledge.

This special report provides background information on the topic of caregiver assessment from various professional perspectives, and also highlights the lived experiences of two family caregivers, Dan Ahern and Carol Levine, who shared their stories at the conference. The personal accounts provide important insights into the direct and powerful consequences of caregiving, and the lack of recognition and assessment of their own support needs.

The four papers were commissioned by leading experts in preparation for the conference to enhance deliberations and inform the exchange during the consensus process. Steven H. Zarit, PhD, focuses on the fundamental question of why, when and how caregivers should be assessed from a research perspective. Nancy Guberman synthesizes the state of the art on caregiver assessment from a practice perspective. Katie Maslow, Carol Levine and Susan Reinhard, PhD, propose policy options for increasing and supporting the use of caregiver assessment in home and community-based programs, as well as in hospital settings and discharge planning. Finally, Anne Montgomery offers an international comparison of the role that caregivers play in assessment processes in the long-term care systems of six countries.

We owe a special debt of gratitude to our authors. Their meaningful papers and personal stories provide a thoughtful presentation of critical issues and perspectives in assessment of family caregivers.

This volume is intended to complement Volume I of this report, *Caregiver Assessment: Principles, Guidelines and Strategies for Change*. That publication includes the professional consensus achieved at the conference. Both documents (Volumes I and II) are available online at [www.caregiver.org](http://www.caregiver.org), or as printed reports, available from Family Caregiver Alliance.

We hope that readers will find this publication a valuable resource for further research, discussion and action to improve policy and practice for America's caregiving families.

Kathleen A. Kelly  
*Executive Director*

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# Voices of Family Caregivers

1

## Holding a Mirror to Caregiving

Dan Ahern, JD, MEd

## Notes from the Edge of the Abyss

Carol Levine, MA

# Holding a Mirror to Caregiving

Dan Ahern, JD, MEd

*M*y name is Dan Ahern. I am a San Franciscan, born and raised. I'm married, have three children under the age of 12 and spent my 30s and part of my 40s as a caregiver to my Mom and Dad. My Mom, Rose, died 13 years ago after a courageous ten-plus year battle with Alzheimer's. My Dad, Dave, died six years ago, the life drained out of him from trying to take care of Mom.

Family Caregiver Alliance asked me to speak to you for ten minutes. You have a lot to do today. I won't take any more time than that.

It's a beautiful September day here in my home town. It's the favorite season of the year for San Franciscans.

But, it's early in the morning, isn't it? Some of you folks here are still waking up. Reviewing the agenda. Making some preliminary decisions about what workshops look interesting. Wondering who in the heck this invited speaker is without any academic or research credentials.

My only admission ticket today is that I was a caregiver and, in many ways, hope to God that I still am.

How many of you here are caregivers? Welcome. How did you sleep last night? Did you get more than ten minutes solid rest? I sure hope so.

Ten minutes. That's all some caregivers ask for now and then. They say, "If I just had ten minutes to myself...."

I'm 51. Twenty-one years ago one of my best friends from childhood, one of my blood brothers, collapsed at home, was rushed to San Francisco General Hospital, where doctors discovered a brain aneurism.... Ten minutes. That's all it took me to drive from my parent's house to SF General and to nearly faint, for the first and only time in my life, at the sight of my friend with tubes in his hastily shorn head.

Today, the same friend still remains in a skilled nursing home. He can't walk. Can't swallow unless prompted. Can't understand that 20 years have passed. Still plans on driving his truck to Tahoe.

Ten minutes. That's all it took for me when I attended my first family support group, hosted way back when by Family Survival Project, to hear that "when someone suffers a brain injury, besides the cognitive and physical losses, he also is vulnerable to the loss of friends and loved ones."

You see, none of us likes to look in a mirror like that. My kids and I are fans of Harry Potter. In one of the books Harry stumbles across the Mirror of Erised. In this magical object, one sees what one desires. It is alluring, truly alluring. And, one can lose one's mind just staring at what one desires...so says wise Professor Dumbledore.

And what fate awaits the caregiver who stares into the brokenness of a loved one and is perhaps reminded of what could be his own fate? Perhaps it is the mirror of mortality.

Twenty one years ago my friend's life changed forever. As did his Mom's life. His Mom is one of my only true heroes in this world. She has weathered a variety of back problems, the occasional mugging, and the whims of three public buses to visit her son nearly every day of his hospitalization. Over these years she has asked for nothing for herself but has fought with every ounce of wit to protect her son's dignity. Without her dedication, her son—my friend—would no doubt have had even more troubles than he has had.

How ironic then, when but one year after my friend's brain aneurysm, my sister's and my worse suspicions about our Mom's faltering memory and odd behavior were confirmed: she was in the middle stages of Alzheimer's disease. Remembering that Family Survival Project (now Family Caregiver Alliance) had information and resources that really hit my heart when I attended their meeting at my friend's nursing home, I placed my first call to them.

They directed me to help that empowered my sister and me to make the best informed decisions that we could make. They helped us think of and even talk about our own survival—and believe me, that is much easier said than done when one is a caregiver, isn't it?

Today, my heart still aches for my parents and I cherish their legacy of love, courage, and dignity. My sister and I do whatever we can for friends and their friends when we're called upon to lend an ear or advice about everything from nursing home placement to dealing with a well-spouse or parent who refuses to accept medical treatment.

The other day I was telling my nine-year-old Donovan and my soon-to-be-11-year-old Elizabeth Rose, that when you love someone, you do what is right. Even if what is right doesn't seem fair or even loving for the person for whom you are making decisions. In thinking about this time with you, I told them how I faked a call to 911 when my Dad refused to be seen for medical treatment for what we thought was a cancerous growth (that ended up being just a horribly infected scab that in his anxiety, depression, and emotional collapse he made worse). When my Dad begged me to call 911 back and cancel the cops, I said, "Dad, I never made the call. I'll do whatever I have to do to get you help even if it means you'll hate me the rest of your

life. You and Mom took care of me and Judy when we were kids and life is such now that it is our turn to take care of you”.

Ten minutes. That’s how long my sister jabbed her finger in my dad’s chest and told him in no uncertain terms that he was going to the hospital (a locked psych unit) for the help he needed.

By the way, did I mention that my fiercely proud son of immigrants Irish father would never let anyone know that he was hurting and needed help?

Ten minutes. Like these ten minutes here.... That’s how long my mother pounded on my chest at the nursing home when she realized that she was going to move in. Ten minutes. That’s how long she cried and screamed at me for “trying to kill” her.

Ten minutes. That’s about one third of the time I cried in the hallway in my sister’s arms when we left Mom in the nursing home by herself.

All I have is ten minutes this morning. And now, half of that is gone. What are you going to do with ten minutes when you have the opportunity as decision-makers, leaders, persuaders, educators and directors?

Will you leave this conference and view caregivers as being extraordinary people who happened to be dealt a tough hand? You see, that’s not what caregivers want from you. What caregivers want and need is the formal recognition, that is the commitment of your intelligence, your resources, and your acknowledgment that without family caregivers, we have missed the real truth to this whole caregiving agenda.

Will you remember what I said about my dear friend in his nursing home and think only of a 50-year-old who will spend each and every remaining day of his life dependent on others for all of his basic daily needs? Or will you please remember his elderly mother too? Will you think of her needs and how she is his lifeline to his sanity and to his emotional well being and who without fanfare has spent the last 20 years of her life re-parenting a man she already raised?

I love being a father. It is the most precious, most gratifying, most rewarding thing I have ever done. Beyond my wildest imagination. And it scares me. I am convinced that one day I will get a knock on my door and that faceless agency in charge of defrocking dads will say, “Excuse me, Dan, we know that you have no stinking idea of what you’re doing as a dad. You’ll have to come with us. Your license has been revoked!” And I’ll go – guilty as charged.

But one of the most valuable lessons I pray to God I’ve learned about parenting I learned from accepting and trying to honor the privilege of taking care of and orchestrating care of both of my parents.

Ten minutes. That’s how long it took me to change my first diaper. Ah, the great sense of relief one conveys when changing a diaper. Any parents here? You

know how rewarding that is right? But it was on my Mom at the nursing home because there were no staff available. I prayed with all my might that I would not compromise my Mother's dignity at that moment. I prayed with all my might that someone, somewhere would one day tell other sons that they may have to change their own mother's diaper.

Ten minutes. Who here has read *Good Night Moon*? What a glorious testament to the ritual of saying goodnight to our innocent children. God how I miss reading that book! But, it only takes about ten minutes, cover to cover. And, in ten minutes one night when I was with my Mom while she was still at her home, she and I talked about a silvery object in the sky. As she pointed out the window of my old bedroom, up at that beautiful orb, my Mom said, "Danny, what do they call that thing?" "Mom, they call that the 'moon'." Dear God, please help me not bawl my eyes out in front of my Mom...that was my silent prayer right then and there.

Ten minutes. That's about how much time was allotted when I first met a U.S. Senator on one of my public policy visits as a volunteer for Family Caregiver Alliance. In that time that very fine elected official told me that he just got finished hearing arguments from colleagues that yachts should be classified for tax purposes as second homes. Then he asked me how he thought I could get the attention of his colleagues whose focus was clearly not on caregiving. I gave him my best in ten minutes – I told him then, as I beseech you now, to look at the caregiver as part of the caring itself. I urged him, and I implore you, *to look at caregivers as the key to caregiving on all levels*. Couch it in financial terms, measure it in lost production, assess it in skyrocketing health claims for the caregiver...compartmentalize it in every rubric you can think of for analyzing a problem and your yield is the same answer. There is no "care" without "caregivers."

Ten minutes. That's how long it took me at my very first support group, hosted by the Alzheimer's Association, to see that what I was up against was much, much bigger than just my faith and love for my parents.

Ten minutes. That's how long it took me to drive to my parents' house one Sunday morning when my dad called and apologized but asked if I wouldn't mind driving him to the hospital to get his head stitched up. You see, because he was so exhausted from getting up several times every night to keep an eye on our then wandering Mom, when he finally dozed off he had a nightmare and fell out of bed and cut open his head on the nightstand.

Ten minutes. That's all it took for me to call the director of the special care unit of my Mom's nursing home and threaten to call the media to see for themselves the travesty of having Alzheimer's patients on a "dedicated unit" be left unattended on a cold and rainy San Francisco night, with no blankets, windows wide open, no heat and not even the faintest attention by the nursing staff—all because someone

forgot to issue a memo that the electricity was turned off for elevator repair. The *coup de gras*: the evening snack was ice cold lemonade!

Epilogue: the next day that same director asked me to help him with in-service training for their nursing aides and would I mind not calling the State Ombudsman? Sorry, pal. Too late for that.

That was then. Today from this conference's list of who's who, I know that I am in the presence of "difference-makers." I heard that term last week on a sports talk show, as "when Harrison is in the game, he is a difference-maker." I am a sports fan. I was even an athlete way back when. But the only outcome I'm interested in is what we, caregivers and you, can achieve by working together. I've never been strong at math but if you were to add up the difference-makers in this room, right here, right now, we'd go even further to protecting the dignity of our loved ones and keep our caregivers doing what they want to do: provide care and comfort to their beloved.

Today and when you leave here, you will need more than ten minutes to digest and appreciate the many excellently researched and written monographs you've received at this conference. You'll need more than ten minutes you'll say, to persuade the other "difference-makers" you know that caregiving is as much about caregivers as it is about the diseases and the victims of those diseases. You see, caregivers really do not want sympathy. We have no time for that.

And, you'll need more than ten minutes to accept your own "mirror of mortality" when you somehow stumble across it on your own journey and wonder how others could possibly cope with such a burden.

And if you are as blessed as I have been during this journey, you will need the rest of your lifetime to come to peace with the both the nightmares of caregiving and the Grace that indeed manifest themselves when you love and hold your Mom's hand as she takes her last breath.

Ten minutes. I thank you for this time. On behalf of my friend and his Mom, my own Mom, Dad, sister and her family and now my own family, I thank Family Caregiver Alliance and its incredible staff for what you have done for us and for caregivers everywhere. To you professionals who gathered in this wonderful city to further this most important cause, I thank you for what you will do.

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# Notes from the Edge of the Abyss

Carol Levine, MA

*I* have been a caregiver for almost 16 years. Many of you have heard me speak or have read my articles about caregiving – how my husband was grievously injured both in body and mind in an automobile accident from which I walked away with only a broken heart, how I began to align my health care and medical ethics career with my personal experience, and how I continue to care for my husband at home.

Not for me the slow dawning of caregiverhood, the gradual assumption of responsibilities as an aging parent declines into frailty or dementia. I was thrown into the black hole of long-term, chronic care for my life partner, my lover, and my best friend and writing critic, and there I remain. However much my relationship with my husband has changed, I am still my children’s mother and their children’s grandmother, relationships I cherish and nurture. I have no extended family-friends-community network of support. For the help I need to keep my husband at home, I have the ultimate in consumer-directed care: I hire, I fire, I pay.

In all these years, through crises major and minor, intensive care, surgeries, rehab, more surgeries, more rehab, short-term home care agency services, I have never had a formal caregiver assessment--that is, if a formal caregiver assessment means a discussion with a professional involved in my husband’s care about my needs, my strengths, my weaknesses, my health, my well-being, my finances, my job, my other family responsibilities. Nor have I had a formal caregiver assessment if that means a series of questions to see whether I am entitled to or would benefit from any publicly funded service.

This does not mean, however, that I have not been assessed. That has happened many times, if an assessment means a discussion *about* me, without my presence or contribution, or a judgment *about* me, based on my demeanor, my attitude, my presumed resources, or whatever else might influence the assessor. In these informal assessments, I have been found to be (a) insufficiently self-sacrificing; (b) too demanding; or (c) so competent that I need no assistance.

Let me give you a few examples.

Throughout the many months my husband was in a rehab facility a team made up of doctors, nurses, PTs, OTs, psychologists, and a social worker met regularly to discuss his case. Although I repeatedly asked to attend these meetings,

I was never allowed to do so. I know that I was discussed at these sessions because soon after they were held I would be informed about how difficult he was to manage and how it was my responsibility to make him more compliant. “Tell him not to shout,” I was told. “Tell him to work harder at PT.” And “If you were here all the time, instead of going to work, he might be less combative.” Remember, this man had just emerged from a four-month coma and had substantial brain injury. Being at his bedside from 4 p.m. to 10 p.m. every day and all day on the weekends, communicating daily with the therapists, bringing music, pictures, calendars, and videos to orient him and stimulate his thinking—all this was not good enough.

At one point I thought things might get better because the psychologist seeing my husband asked if she could see me. “At last,” I thought, “someone who will understand what it’s like to go through this nightmare.” When I sat down in her office, she started the conversation by saying, “We would like to know why you are not more involved in your husband’s care.” And then things got worse. Her job, as she understood it, was to act as my husband’s spokesperson, riding roughshod over my self-esteem and my identity, in the interests of establishing that his needs came first, last, now, and forever. The culture of this rehab facility seemed to be to indoctrinate the caregiver into the role brusquely and, if necessary, brutally. There is a classic article called “Hate in the Rehabilitation Setting.” I can attest that it exists. I felt hated, and I hated that I hated in return.

The social worker in the rehab facility repeatedly told me that I should “get real” and “stop working, spend down, and get on Medicaid.” I refused all of the above and said I would not take him home without some guarantee of home care. He was a two-person transfer, (that is, not a job for any person on her own), incontinent, requiring maximum assistance in everything. He was either in a rage or catatonic. Think Christopher Reeve without the charisma and charm—and without the resources to hire multiple, round-the clock helpers. Eventually my lawyer did get some promise of home care through my husband’s employer-based insurance, promptly broken when we got home, of course, but at least we made the transition.

At other times when I was able to get a little paid home care—respiratory therapy, for example—the assessment involved a quick look around my pleasant apartment, books on the shelves, clean kitchen and bathrooms, and a brief conversation in which I speak in complete English sentences. “No problems here!” I can sense the therapist’s relief. The self-protective mechanism seems to be: don’t ask questions. Don’t go near the abyss. There might be chaos and despair just below the surface, and you might get caught in the undertow.

I don’t blame the home care workers for making these quick judgments. They have nothing else to go on but intuition and experience. At the United Hospital Fund we recently completed a major study of caregivers’ transitions when formal home care services are terminated. One arm included a series of focus groups with

clinicians. Nurses, social workers, PTs, OTs all said things like, “As soon as I open the door, I can tell what this family is going to be like—cooperative, really nice, or hostile and dysfunctional.” And through the magic of the self-fulfilling prophecy, they are usually right. Staff need better tools to more systematically and without stereotypes assess the caregiver’s strengths and limitations and to plan for services accordingly, to the extent possible, and to suggest other resources where available.

While I understand the value of consistency and uniformity in assessments, whatever instruments are used should also be flexible enough to accommodate specific information about caregivers. When I began to read the caregiving literature, way back in the early 90s, I was baffled by the emphasis on ADLs and IADLs. What were these things anyway? And why did professionals think that this was the core of the caregiving experience? My husband needs maximum assistance in all the Activities of Daily Living—bathing, eating, transferring, and the rest—and I do all the Instrumental Activities of Daily Living—shopping, bill-paying, telephone calling, and so on. If anyone needs help in ADLs and IADLs, it’s me. But that’s just part of what I do, or manage, or pay for, much less go through. Where is the question about dealing with the hospital, transportation company, insurance company? Where is the question about WHEN do you do all these things? Who asks about sleep deprivation?

Where are the questions about degree of difficulty in, for example, bathing? Where is the question about “just being there, waiting for the next time to do something, the next time there is a call for water, changing the TV channel, fixing the pillow, or any of countless uncategorizable requests? One of the participants in our study – a man caring for his father -- described this as being on “lockdown.” I can relate to that.

My early dissatisfaction with ADLs and IADLs as a measure of caregiving activities led to a United Hospital Fund project supported by the Robert Wood Johnson Foundation and a book called “Family Caregivers on the Job: Moving Beyond ADLs and IADLs,” which the Fund published in 2004 and which was a precursor to this consensus conference. What lies beyond ADLs and IADLs is all the stuff of human relationships, dealing with an indifferent and unresponsive health care system, trying to maintain a semblance of normality when your home has become not a safe haven but a mini-hospital clinic, when you as the caregiver are always at the edge of the abyss.

There are so many aspects of caregiving and different people approach them in different ways: they may enjoy it, tolerate it, cannot physically or intellectually do it, or absolutely find it abhorrent. Shouldn’t an assessment ask about the caregiver’s reaction to different tasks, instead of just whether they do it or not, and how many hours or minutes it takes?

On one occasion, after minor but unpleasant surgery for a cyst on my husband’s back, the home care nurse took out a long implement and began probing

the deep wound. “This is how you clean the site,” she said. “No,” I said, “This is how *you* clean the site. I’m not a nurse and I’m not trained to do this.” “Wife refuses to provide care,” she wrote on the form, but she did come back until the wound was partially healed and I could take over.

Another caregiver might have had no problem with that level of nursing care but couldn’t manage all the financial aspects of care. Most of us, I think, sit on one side or other of the personal care and incontinence divide — “I won’t, I can’t” or “What’s the big deal?” We’re also on one side or another of the “personal rewards” divide. Some may say, “It’s so gratifying, I’ve become a better person” or, as a devoted caregiver in our study said, “Rewards? What kind of a stupid question is that!” We are entitled to respect from professionals – and from each other – for these different perspectives.

Finding ways to relieve a caregiver of aspects of caregiving he or she finds most onerous would go a long way toward preventing exhaustion and burnout and delaying nursing home placement. But in order to do this, someone has to ask the right questions.

I trust that at the end of this conference we will all have a better idea of what are the right questions, who should be asking them, and how we change practice and policy to bring caregiver assessment to its rightful place in the health care and social service arenas.

# Views from the Field

## A Research Perspective

Steven H. Zarit, PhD

## A Practice Perspective

Nancy Guberman, MSW

## A Policy Perspective

Katie Maslow, MSW, Carol Levine, MA,  
and Susan Reinhard, PhD, RN

## An International Comparison Across Six Countries

Anne Montgomery, MS

# Assessment of Family Caregivers: A Research Perspective

Steven H. Zarit, PhD

## Abstract

This paper focuses on the fundamental questions of why, when and how caregivers should be assessed. It provides a conceptual foundation for caregiver assessment and the selection of domains for inclusion in an assessment. There is no “best” assessment battery that fits every situation. Instead, a multidimensional model of caregiver stress can guide assessment design for a particular program and given population. The stress process model of caregiving (SPM) provides a useful framework for assessment, differentiating among the different types of stressors that caregivers face, resources that can ameliorate specific stressors, and outcomes for the caregiver’s health and well-being. A case example is used to illustrate how assessment can be tailored to identify specific goals and hypothesized effects. Conclusions about the implications of research for assessment of caregivers and recommendations for the future are offered.



## Introduction

Although the charge given to me is to discuss research perspectives on assessing caregivers, a discussion of research cannot be divorced from consideration of clinical principles and perspectives. I was trained both as a researcher and a clinician, and worked for several years directing a program that provided services to family caregivers. From my experiences in both realms, I believe that it is possible and necessary to bridge the usual gap between research and practice in order to deliver the best possible services for older people and their caregivers.

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## Purpose and Structure of Paper

This paper will begin by addressing the fundamental question of why and when caregivers should be assessed. Next, I will discuss a framework for assessment, including which domains might be assessed and practical issues in conducting assessments. I will also give an example of how the use of a conceptual model of assessment was useful in planning a study of the outcomes of a service program.

My goal is to provide a conceptual foundation for why caregivers should be assessed and what possible domains should be assessed. I will emphasize two main points throughout. First, the implications of research as well as principles of good practice unequivocally support the premise that assessing caregivers is a necessary and essential part of working with older clients in virtually every setting. Second, while assessment of caregivers should be a basic component of a program, there is no “best” assessment battery that fits every situation. Although there may be a core of common information that almost everyone would want to obtain, the task of trying to fit all programs and services to a broad-based assessment tool would likely yield time-wasting procedures that do not give programs the information they need. A better approach is to utilize the principles of caregiver assessment to devise a battery tailored to the specific needs of a particular program and service and to the populations served.

Another fundamental issue is that an assessment battery needs to include options that assess disease-specific characteristics. If you went to the doctor because of pain in the back, you would expect an evaluation of the symptom, not a general health screening. In the same way, a psychosocial assessment needs to target the relevant problems, obtaining information for identifying those problems accurately and planning an intervention for that problem. Sometimes that information has to do with a client’s underlying disease and/or with the specific functional problems associated with that disease. Negative outcomes are particularly common among family caregivers of persons with dementia, so my discussion of assessment topics and measures includes issues, such as behavioral problems, that are primarily a consideration with dementia.

Finally, I will give examples of measures for specific domains, but I will not provide a comprehensive review of measures. That has been done extensively in other places (e.g., Brodaty, Green, Banerjee et al., 2002; Feinberg, 2004; Family Caregiver Alliance, 2002; Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003).

## Why and When Should Caregivers Be Assessed?

### Research Evidence on the Need for Assessment of Caregivers

Caregiver assessment is an essential component of working with older people, particularly those with cognitive problems. The importance of assessing caregivers is underscored both by research findings as well as best practice approaches with older adults.

Caregivers face an array of problems that can quickly erode their physical, psychological and financial resources. Research over the past 25 years has documented exhaustively that care of older persons with dementia and with other cognitive and emotional problems is extremely challenging and stressful for family caregivers (e.g., Aneshensel, Pearlin, Mullen, Zarit, &

Caregiver assessment is an essential component of working with older people, particularly those with cognitive problems. The importance of assessing caregivers is underscored both by research findings as well as best practice approaches with older adults.

Whitlatch, 1995; Anthony-Bergstone, Zarit, & Gatz, 1988; Max, Weber, & Fox, 1995; Pruchno, Kleban, Michaels, & Dempsey, 1990; Schulz, Visintainer & Williamson, 1990; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Schulz & Beach, 1999; Wright, Clipp & George, 1993). Caregivers suffer from high rates of depressive and anxiety symptoms and feelings of anger when compared to people matched on age and gender who are not caregivers. Estimates show that between 40 to 70 percent of caregivers of older adults with various types of disorders have clinically significant symptoms of depression, with approximately one quarter to one half of these caregivers meeting the diagnostic criteria for major depression (Coppel, Burton, Becker,

Estimates show that between 40 to 70 percent of caregivers of older adults with various types of disorders have clinically significant symptoms of depression, with approximately one quarter to one half of these caregivers meeting the diagnostic criteria for major depression.

& Fiore, 1985; Drinka, Smith & Drinka, 1987; Gallagher, Rose, Rivera, Lovett & Thompson, 1989; Redinbaugh, MacCallum & Kiecolt-Glaser, 1995). Symptoms of anger and anxiety are also quite common. These mental health

symptoms, in turn, may be part of a cascading process in which caregivers become demoralized and exhausted. Higher depression and other care-related strain increase the likelihood that caregivers will yield the caregiving role and place their relative in a nursing home (e.g., Aneshensel et al., 1995; Gaugler et al., 2000). The chronic stress of

assisting a relative with significant disabilities can also lead to physiological changes, increased medical illness and a greater risk of mortality compared to age and gender-matched controls (Schulz & Beach, 1999).

Caregivers' lives can be affected in a variety of other ways as well. Caregivers who are employed outside the home may experience lost wages or even leave the workforce entirely. Care demands can lead to marital and family conflict (Semple, 1992). Leisure, social and religious activities may be abandoned. Caregivers may even find their sense of identity absorbed in the caregiving role.

These findings are dramatic and indisputable. They clearly suggest the need to consider both the "patient" and the caregiver in assessments. From the earliest studies, family caregivers were characterized as the "hidden patients" who needed care themselves to address the impact their relative's illness was having on them (Thompson & Doll, 1982; Zarit, Orr, & Zarit, 1985).

Higher depression and other care-related strain increase the likelihood that caregivers will yield the caregiving role and place their relative in a nursing home.

## Clinical Perspectives on Caregiver Assessment

**Whose Problem Is It?** From a practice perspective, there are also compelling reasons to focus on caregivers. In a landmark paper, Kanfer and Saslow (1965) posed a central question for assessment, "Whose problem is it?" They observed that people who seek help often ask providers to "fix" someone else's problems. The person who is bringing the problem to the attention of the clinician, however, has defined the situation as a problem. The designated "patient" may deny there is anything wrong. When the "patient" is unwilling or unable to participate in treatment, the best course is to help the person who initiates the contact to deal more effectively with the situation.

This assessment principle applies in many clinical situations involving older adults, particularly when the identified client suffers from a cognitive impairment (Zarit, 1980; Zarit & Zarit, 1998). Except during the earliest stages of dementia, people with cognitive impairment rarely seek help for themselves. Instead, a family member or other concerned individual seeks help on their behalf, *and/or* because the problems have begun to impact on the family member's life. The specific problems presented depend on the family member's appraisal of the situation and of his/her own responsibility for that older person. The older person, however, usually does not acknowledge these problems and may even resist or resent the family member's intervention. Furthermore, the potential solutions almost always involve working with the caregiver to make changes in the situation. The caregiver must take responsibility and

action, whether the goal is obtaining and giving medications to the patient, learning to cope more effectively with dementia-related problems or letting a service provider into the home. In effect, caregivers present problems that trouble them and seek help to relieve their concerns and distress. To not assess them in a systematic way is to obscure the real focus of the problem as an interaction of older person and family member.

**Benefits of Caregiver Assessment.** A structured assessment of caregivers can contribute to clinical settings in several ways. First, a systematic assessment will make it possible to identify clearly and precisely what problems are present in the situation. Second, the assessment can clarify the family's role and resources for caregiving, as well as the strains that care is placing on their lives. Rather than making inferences about the family's needs, this information should be obtained in a direct way. Third, an assessment may reveal that the caregiver has pressing personal needs that should be addressed. Finally, the goal of many interventions is, directly or indirectly, to relieve stress of family caregivers. An assessment can provide evidence of need as well as of the effectiveness of the intervention in addressing the caregiver's problems.

I have sometimes encountered programs that are reluctant to involve caregivers or to even ask them a few questions. After having conducted thousands of clinical and research interviews with family caregivers, my experience has been that most of them want to be involved and do not mind even a lengthy assessment interview. When a caregiver does not want to be involved, and imagines that he/she can just drop the older person off to be taken care of, that is itself valuable clinical information that needs to be taken into account in planning treatment.

A recent study demonstrates the benefits from use of a caregiver assessment instrument (Guberman, Nicholas, Nolan, Rembicki, Lundh & Keefe, 2003). Across service settings in three countries, it found that assessment of caregivers helped identify important issues that otherwise might have been overlooked and improved the focus of the information collected. Conducting the assessment also gave the family a defined role in the treatment process and validated their knowledge and experiences. In other words, families recognize that they are already involved when they bring an older person in for treatment.

From both research and clinical perspectives, then, involving the caregiver is an indispensable part of the overall assessment process. A successful intervention will often begin with the caregiver, and not just the patient, whose ability to respond to treatment may be more limited.

## Should Every Caregiver Be Assessed?

Should caregivers always be assessed? A fundamental goal for clinical practice with older adults is to support autonomy and independence whenever possible. Just as it is poor practice to talk only to an older client suffering from dementia and ignore the perspective of the family members who brought the elder to the clinic, it is not appropriate to disregard the perspective of the older person. When an older client is competent to make decisions, a family member cannot be involved without the specific consent of the client. People with early, mild dementia and with chronic mental illness can retain the competency to manage their own health care and other affairs. Even when an older person cannot report accurately, as in cases of more advanced dementia, we always treat them with respect and give them time to tell their story.

## Generic versus Disease-Specific Assessments

Another fundamental issue is whether it is possible to conduct a generic assessment for all caregivers or if assessments should be disease-specific. As noted already, disease and/or problem-specific information is necessary and essential. When agencies serve a heterogeneous population, a single instrument is unlikely to be informative for every client. It is possible, however, to build an assessment tool with branch points that, depending on the caregiver's responses, lead into specific inquiries about the problems that this client's relative has. That is what good clinicians have always done in conducting an assessment. Even if an agency only served one type of client (e.g., families of people with dementia), branching points in the assessment still would be needed to allow for investigation of the relevant variability in each person's situation.

## Assessment as an Ongoing Process

There are good reasons to consider regular reassessments of family caregivers. Caregiving is often a long-term commitment, spanning a period of several years. Changes in the elder's or caregiver's health and functioning may necessitate altering the treatment approach or the mix of services. Reassessment also creates the opportunity to evaluate if treatment was implemented as planned, how well it has been working, whether goals have been reached and if there are any unmet needs. The frequency of reassessment depends on

Reassessment also creates the opportunity to evaluate if treatment was implemented as planned, how well it has been working, whether goals have been reached and if there are any unmet needs.

the population and goals of the program. It also can involve an abbreviated version of the original assessment instrument, thereby reducing the time demands on caregivers and the service agency.

## Domains for Assessing Caregivers

Research provides a useful framework for identifying the domains to consider in developing assessments for caregivers.

## Multidimensional Model of Stress

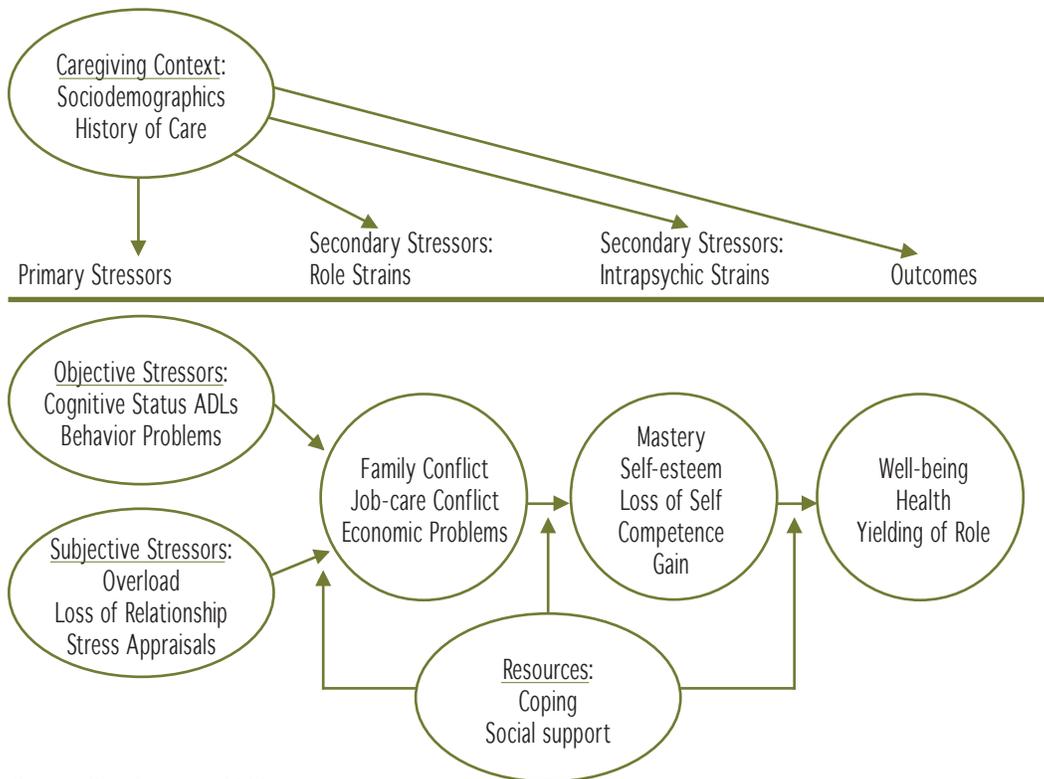
Many people discuss the stress or burden on caregivers as if it were a single entity, assuming we only need to ask a few questions or use a single measure of stress to gather the information we need about caregivers. Caregiving stress, however, is a multidimensional process (e.g., Aneshensel et al., 1995; Pearlin, Mullan, Semple & Skaff, 1990; Lawton, Brody & Saperstein, 1989; Vitaliano, Maiuro, Ochs, & Russo, 1989). In other words, caregiving can result in many different kinds of stress. If we focus on identifying one dimension of caregiving stress, we may omit another dimension that is really critical in a particular person's situation. No single measure, whether of behavior or cognitive problems, ADL impairment, burden or anything else, can encompass the many ways that people caring for an older relative might be affected.

Using a multidimensional model of caregiving stress to guide assessment has three main advantages. First, these multidimensional models can identify which dimensions might be included in an assessment. A model can help us think about the domains that would be most important for treatment planning and identify dimensions not immediately obvious or that we might not otherwise have considered. Second, a model can differentiate among distinct features of the stress process. Some measures combine, often in unsystematic ways, several different domains or aspects of stress. These composite measures have limited usefulness because it is not clear to what extent each aspect or dimension contributes most to the total score. Specific measures are also more useful for evaluating treatment outcomes, because they can target the precise changes occurring as a result of a particular intervention. Third, use of a multidimensional model of the stress process can help service providers think more precisely about what effects they are likely to be having on clients and family caregivers. In other words, before drawing up an assessment battery, it is important to examine the assumptions we have about how a program or intervention works, what is likely to change and why. Identifying these hypothesized treatment mechanisms makes it possible to design a specific assessment battery useful for evaluating the need for this treatment, and for obtaining good outcome data on the program's benefits.

Using a comprehensive, multidimensional model as a guide does not mean incorporating every feature of the model into the assessment battery. Some dimensions will not be relevant to the program or agency. The reason to begin with a conceptual model, in fact, is to identify those processes which are most important for a particular program, and then tailor the assessment around them.

**Stress Process Model.** There are several useful models of caregiving stress in the literature (e.g., Aneshensel et al., 1995; Pearlin et al., 1990; Lawton et al., 1989; Vitaliano, et al., 1989; Yates, Tennstedt & Chang, 1999), but I find Pearlin’s Stress Process Model (SPM) the most helpful for guiding assessment. The SPM has five main components: (1) caregiving context; (2) primary stressors; (3) secondary stressors; (4) resources; and (5) outcomes (see Figure 1). Each component of the model will be described briefly, with examples of measures (see Pearlin et al., 1990; Aneshensel et al., 1995, for more complete discussions, and Zarit & Leitsch, 2001, for application of the model to design and evaluation of services and other interventions). More comprehensive lists of measures are available from several sources (e.g., Brodaty et al., 2002; Feinberg, 2004; Family Caregiver Alliance, 2002; Deeken et al., 2003).

Figure 1: Pearlin’s Stress Process Model



Sources: Pearlin, et al., 1990  
Aneshensel et al., 1995

## Caregiving Context

Caregiving context includes social and demographic characteristics of the caregiver and person needing care, such as age, education, gender and whether the caregiver is employed outside the home. Context also includes the history of the illness or problem and the history of caregiving, specifically, when a problem was first noticed, was a medical diagnosis made (and when) and how long the person has provided care.

Perhaps the most important contextual features have to do with caregiving arrangements, that is, whether the caregiver is primary or secondary, and the kin relationship between caregiver and older person. Often it is clear that the person who accompanies an elder to an appointment is the primary caregiver, that is, the individual who has the main responsibility for providing care and making decisions. Sometimes that is not the case. A daughter may accompany a parent to an appointment, but the other parent who has not come is really the person who gives most of the care. In that event, it is usually necessary to talk directly with the caregiving parent in order to understand the situation. Sometimes there are disagreements over who should be in charge of an elder's care. Two siblings, for example, might both want to be in charge of care, or, conversely, want the other person to take on the lion's share of the responsibility. Finally, some families work out shared caregiving arrangements.

When the primary caregiver has accompanied the older person, it is still useful to determine what other family members are involved. These secondary caregivers may be helpful or may add to the primary caregiver's stress.

Kin relationship, whether the caregiver is a spouse, daughter or other relative, probably makes more difference than any other factor in determining the degree of commitment to providing care. When there is a competent spouse, that person

**K**in relationship, whether the caregiver is a spouse, daughter or other relative, probably makes more difference than any other factor in determining the degree of commitment to providing care.

almost always is the primary caregiver and needs to be involved in assessment and treatment. With children, including daughters-in-law, the degree of commitment is more varied. We know least about the motivation and commitment

of other relatives and non-kin who take on the role. Clinical experience suggests some of these people are very involved, others have limited time and interest in caregiving responsibilities, and a few may be exploiting the older person.

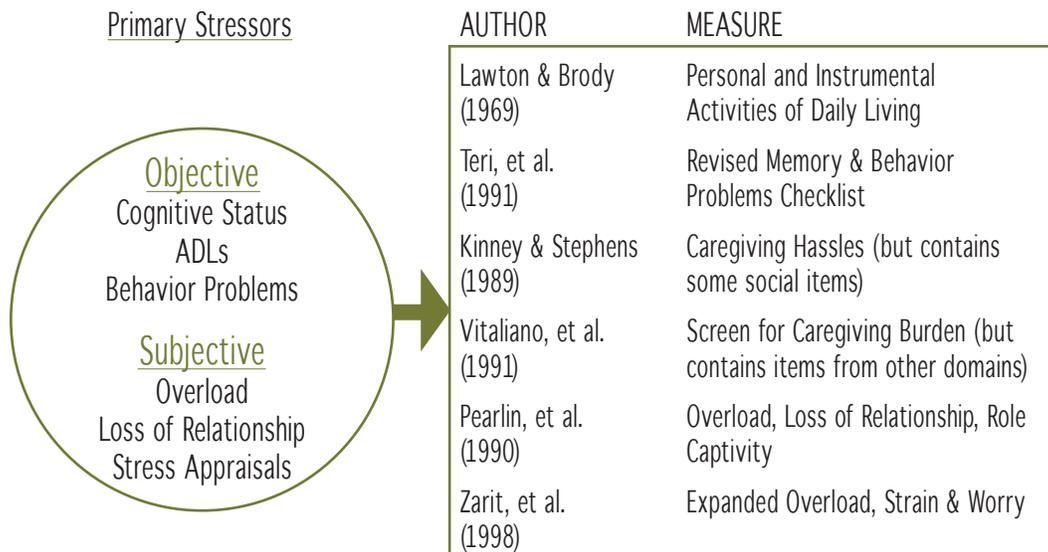
## Primary and Secondary Stressors

**Primary Stressors.** Events and experiences that derive directly from the person’s illness are primary stressors. Consistent with most theoretical models of stress, Pearlin et al. (1990) distinguish between objective and subjective components of primary stressors (Figure 2).

Objective primary stressors include ability to perform activities of daily living (ADLs), cognitive deficits and behavior problems. Assessments typically determine if these problems are present and how severe (in the case of ADL problems) or how often they occur (for memory and behavior problems). Knowing what deficits or problems are occurring is very important for planning treatment.

We also need to know about the subjective impact these stressors have on caregivers. Caregivers vary considerably in what they find stressful. Some caregivers, for example, become overwhelmed when a relative with dementia becomes incontinent, but many manage incontinence without much difficulty. Even for problems that most of us would agree would be very difficult to manage, such as being awakened frequently at night, there will be caregivers who are able to manage effectively. This subjective component is essential for planning and evaluating treatment. We

Figure 2: Examples of Measures of Primary Stressors



should target interventions to the problems that caregivers find stressful, not to the ones that we think are stressful.

There are several ways of capturing this subjective component of stressors (Figure 2). One approach, building on the work of Lazarus and Folkman (1984), is to assess the degree to which the caregiver perceives each event (ADL impairment, cognitive difficulties, behavior problems) to be a “hassle” (e.g., Kinney & Stephens, 1989; Vitaliano, Russo, Young, Becker & Maiuro, 1991) or upsetting (Teri et al., 1992). Another approach focuses on three processes affected by primary stressors: role overload, role cap-

We should target interventions to the problems that caregivers find stressful, not to the ones that we think are stressful.

tivity and loss of the relationship (Pearlin et al., 1990). Role overload assesses the impact that caring has on the caregiver’s time and energy. A sample item is “I have more things to do than I can handle.” Role captivity represents a feeling of being trapped or unable to lead one’s own life. The third measure, loss of the relationship, examines caregivers’ perception of the extent that they have lost intimacy and social exchanges with the ill person. This focus on the relationship is an important yet typically overlooked aspect of caregiving.

**Secondary Stressors.** According to the SPM, primary stressors spill over or “proliferate” into other areas of the person’s life. Secondary stressors are not secondary in terms of their importance. Indeed, any of these areas may be quite stressful for a particular caregiver. Rather, they are called “secondary” because they do not

arise directly in the patient’s illness. Pearlin and colleagues (1990) propose two types of secondary stressors, role strains and intrapsychic strains (see Figure 3). Role strains are the tensions and conflict arising from maintaining other roles in one’s life, such as employment

The fact that a caregiver occupies multiple roles does not necessarily mean that he/she will experience strain in those roles.

and family relationships. Pearlin et al. (1990) include economic or financial strain in this category.

The extent to which caregivers may experience role strains varies considerably. The fact that a caregiver occupies multiple roles does not necessarily mean that he/she will experience strain in those roles. For example, less than half of caregivers experience conflict in their family or work roles (Stephens, Townsend, Martire & Druly, 2001). Some caregivers report that work may actually buffer the impact of caregiving, giving them time away from the patient (Aneshensel, et al., 1995; Stephens, Townsend, Matire & Druley, 2001).

From the perspective of assessment, it is relevant to identify what other roles caregivers have, including if they are married, if they have children or grandchildren, if they have care responsibilities for children, grandchildren or anyone else, and if

they are employed outside the home. It is then possible to assess to what extent their caregiving activities may be leading to conflict or tension in performing these other roles (see Figure 3). It is also important to determine the family’s financial resources and, particularly, the extent to which care-related expenses or the loss of employment income place a strain on the family.

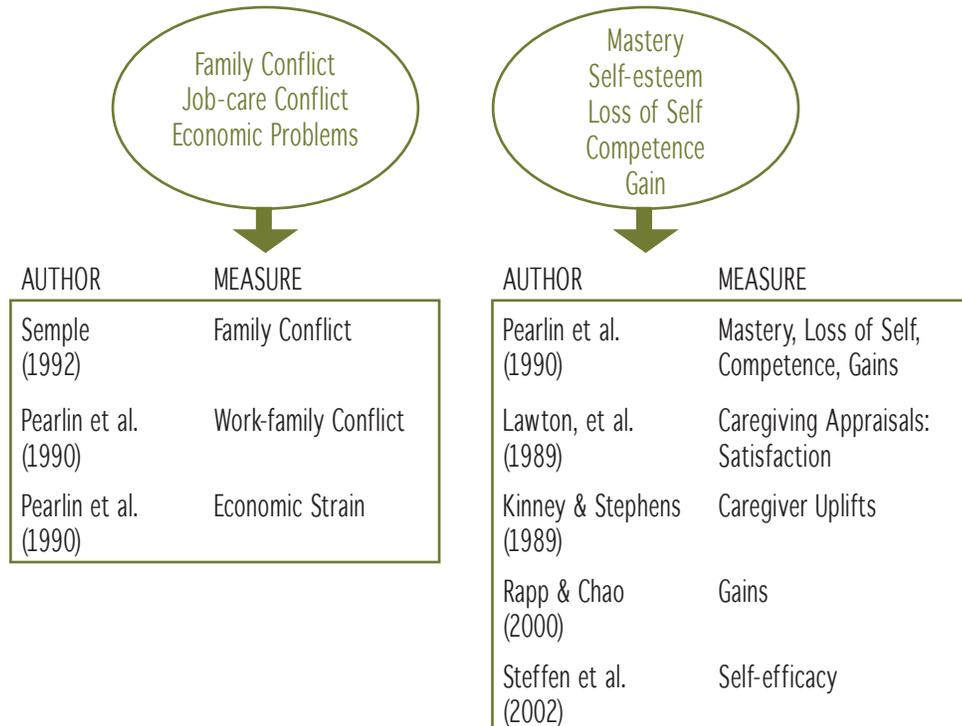
Intrapsychic strains arise when primary stressors begin to erode a person’s self-concept. Erosion can occur in five domains: mastery, self-esteem, competence in the caregiving role, feelings of gain in caregiving and one’s sense of self (Pearlin et al., 1990; see Figure 3). Probably more than role strain, the erosion of self-concept has more direct and deleterious impact on well-being. In particular, erosion of one’s sense of self can lead to a cascading deterioration in other psychological domains (Skaff & Pearlin, 1992).

Although the SPM stresses the potential for deterioration in these areas, interest is increasing in the possibility that caregivers can experience improvements in some of these areas, such as achieving a sense of gain or satisfaction from one’s activities. It has been hypothesized that these positive experiences may help buffer some of the adverse effects of care-related stressors (Rapp & Chao, 2000; Lawton et al., 1989).

Figure 3: Secondary Role Strains and Intrapsychic Strains

Caregiving Context

Primary Stressors    Secondary Role Strains    Secondary Intrapsychic Strains    Outcomes



## Psychological and Social Resources

The resources that caregivers have can lessen the impact of stressors on well-being. Two types of resources have been investigated extensively: coping and social support. Coping includes how well caregivers manage primary stressors such as behavior problems as well as their ways of dealing with the multiple roles in their lives. Some caregivers take an organized and efficient approach to the demands placed on them, while others become passive and paralyzed or even make things worse by lashing out at the patient or other family members. Many interventions have been designed to improve how caregivers manage these various problems (e.g., Whitlatch, Zarit, & von Eye, 1991; Mittelman et al., 1995; Mittelman, Roth, Coon & Haley, 2004; Schulz et al., 2003).

**Coping.** Lazarus and Folkman (1984) developed concepts of coping from which most measures have been derived. Their formulation differentiated between problem-focused and emotion-focused coping. Problem-focused coping involves generating strategies to solve a problem, while emotion-focused coping involves managing the emotional response to stressors. Although problem-focused coping tends to be viewed as more adaptive, emotion-focused coping can be a better strategy when it is not possible to have a direct effect on a stressor. People can also use cognitive strategies, which involve reframing events, or changing one's goals (e.g., Schulz, Wrosch, & Heckhausen, 2003). As an example, a caregiver who is faced with limited time for leisure activities might rationalize that it would be best to put them off while a spouse or parent needed care.

There are some general measures of coping, but Lazarus and Folkman (1984) and others have maintained that coping is not a trait applicable in similar ways in every situation. Rather, coping is seen as a situation-specific response. As a result, the available measures of coping usually assess tendencies to behave in certain ways and may not be specific enough to identify how a caregiver will actually behave in critical situations. One caregiver-specific coping measure has been developed (Nolan, Grant, & Keady, 1995). Another approach to assessing coping is to ask open-ended questions to determine what caregivers are doing and thinking when confronted with the situations they find most difficult or pressing.

**Social Support.** Like many other constructs, social support is multidimensional. Two broad dimensions relevant for assessment are the sources and types of support. Social support can be provided by informal sources, that is, from other family members, friends or volunteers, and from formal, paid helpers. The types of support include information, material (e.g., financial support), instrumental and emotional.

Assessment of informal support from family and other sources includes who helps and what help they provide, and who doesn't help and why.

Assessment of informal support from family and other sources includes who helps and what help they provide, and who doesn't help and why. How much people do is important, but so are the ways in which they provide help, whether willingly or reluctantly, and whether the help directly addresses the caregiver's needs. Family members are often quick to give advice, and though well-meaning, this advice may actually make caregivers feel worse (MaloneBeach & Zarit, 1995). Information about how the family functions, that is, how well they get along and how they solve problems, can also be useful. There are also measures of caregivers' perceived emotional support (e.g., Pearlin et al., 1990). Interventions that increase the useful help that families give the primary caregiver, and reduce family conflict, have been among the most successful in improving the caregiver's well-being (Eisdorfer et al., 2003; Mittelman et al., 1995; Mittelman, Ferris, Shulman, Steinberg & Levin, 1996; Mittelman, et al., 2004; Whitlatch, et al., 1991).

Formal services are assessed in a similar way, determining what help is being provided by whom and how often. Information about costs, particularly if caregivers are experiencing financial burden, would also be relevant. Formal services encompass a wide range of community programs: care management, home health, home respite, adult day services and transportation, among others. Caregivers may have previously had bad experiences with a program they used. For that reason, it can be helpful to ask what services they may have tried previously and what difficulties they might have encountered with past or current programs.

## Outcomes of Caregiving

The final domain is the outcomes of caregiving. Outcomes in the SPM are changes in health and emotional well-being, and nursing home placement. Other relevant outcomes are utilization of health care services and the costs of services.

**Health.** Simple ratings of subjective health typically measure health. More relevant is whether caregivers perceive their health to be changing, if they currently have any health problems, including diagnosed illnesses and symptoms, and if they are getting treatment currently for these problems. With their heavy caregiving demands, at least some people put off going to the doctor or taking care of their health needs in other ways. Some caregivers may also engage in behaviors that worsen their health, such as overuse of alcohol and drugs, lack of exercise and poor nutrition.

**Emotional Well-Being.** The most frequently assessed domain for emotional well-being is depression. The Center for Epidemiological Studies Depression Scale (CES-D; Radloff, 1977) has been widely used in caregiving studies. Easy to administer, it includes cut-off scores for when people should be referred for treatment for depression. People experience emotional distress, however, in different ways. Some caregiv-

ers may get angry or worry and become anxious (Anthony-Bergstone, Zarit, & Gatz, 1988). These other emotional domains should also be assessed.

**Facility Placement.** Another important outcome is placement of the elder in a nursing home or other care facility. From a policy perspective, helping caregivers keep a relative at home has been viewed as a positive outcome, since it is associated with lower costs. Of course, home care is not an unequivocal positive outcome. Sustained home care can be detrimental to caregivers, if they do not have sufficient resources to provide the help that is needed (Aneshensel et al., 1995), and detrimental to elders if there is abuse or neglect.

Delay of institutionalization is a problematic measure of program outcome for another reason. Caregivers often put off using formal services until fairly late in the disease process. As a result, some of these caregivers turn to formal programs such as adult day care as a last resort after they are already burned out, or as a kind of trial for placement (Zarit, Stephens, Townsend, Greene & Leitsch, 1999). The result is an association between service use and increased placement. Helping caregivers keep someone at home when the caregiver wants to do so, and can manage without undue cost, is a worthwhile goal. That type of outcome, however, needs to be differentiated from other situations where caregivers do not want to continue providing home care or have already made up their mind before beginning a service program. Delay of institutionalization, then, is a useful measure when that is both the caregiver's goal and a target of the intervention.

**Service Utilization and Cost.** Finally, service utilization and costs are relevant outcomes for many interventions. The amount of service provided as well as its cost can be assessed. An assessment also can be made of whether the costs of providing assistance are offset by savings in some other area; for example, does lowering the primary caregiver's stress lead to lower use of medical services for either caregiver or patient?

## The Place of Burden in Caregiver Assessment

In reviewing this assessment framework, I have mostly avoided the term "burden". Researchers have defined burden in so many different ways that it has lost its usefulness as a construct. At one time or another, virtually every dimension of the stress process (primary stressors, secondary stressors, outcomes) has been referred to as burden. Rather than adding further to the confusion by suggesting the inclusion of burden measures in an assessment battery, I recommend instead thinking carefully about which domains in the stress process should be included. In some cases, burden measures may provide a very good assessment of the specific domains under consideration, but for conceptual clarity, it is best to start with an understanding of the specific processes to be included as part of the assessment.

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## Use of the Stress Process Model to Guide Assessment

I want to highlight how an assessment can be tailored to identify the specific goals and hypothesized effects of a particular program.

A clear and realistic examination of what a program can accomplish will lead to a more focused assessment that, in turn, will be more useful for planning treatment and for providing evidence about the program's effectiveness. In situations like those faced by family caregivers, where many potential factors contribute to stress, it would take considerable resources to address every aspect of the stress process. A program with limited resources is not likely to have an impact in every relevant domain, but it may be able to treat one aspect of the situation well. A program that sets one specific goal and achieves it will make a better contribution than another that tries to do everything, but fails to commit enough resources to accomplish any specific objective.

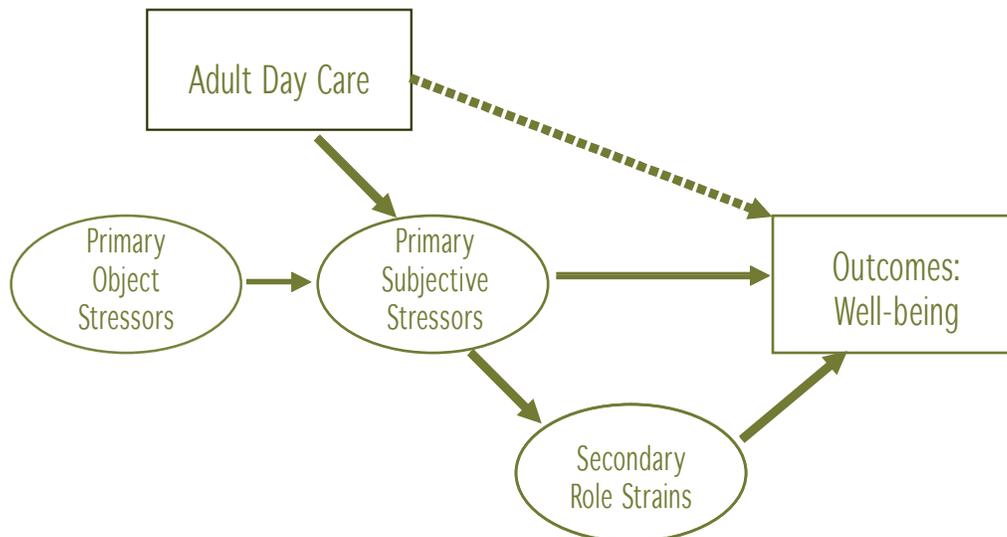
### Case Example

**Goals Clarification.** As an example of the value of clarifying goals, my colleagues and I conducted an evaluation of adult day services for caregivers of people with dementia (Zarit, Stephens, Townsend, & Greene, 1998). As in many programs, the program directors and staff providing adult day services identified many potential benefits that the program might have. The benefits were often quite broad and addressed many dimensions in the stress process. Prior studies, however, that had used global measures to assess outcomes, had not found much evidence for benefits. Cautioned by this knowledge, my colleagues and I spent considerable time thinking about what the effects of adult day services were.

We decided that the immediate impact of adult day services is to provide a predictable amount of time that caregivers can use for other activities. Using the SPM as a framework, we felt that giving caregivers a block of time to do other things would have its biggest impact on primary subjective stressors, that is, that caregivers would experience lower feelings of overload and less strain or tension when trying to get everything done (Figure 4).

We also gave considerable thought to the issue of dosage, in other words, how much day care was necessary to have beneficial effects for caregivers. Drawing upon the clinical experience of program staff, we set a minimum threshold for therapeutic effects—twice a week for three months or more. Although not directly related to caregiver assessment, treatment dosage gets at the issue of what a program might actually be able to accomplish. In addition to measuring primary subjective stressors, we also assessed some other domains to help understand the caregiver's experience

Figure 4: Using the SPM to Guide Assessment and Evaluation



better, particularly depression, anger and positive emotion, but we thought these domains would not be affected directly by adult day service use.

**Results.** Our results showed that caregivers using adult day services twice a week for three months or more had significantly lower feelings of overload and strain. To our surprise, we also found reductions in feelings of depression and anger, more global results that we did not expect.

**Implications.** The point of this example is the importance of thinking carefully about what an intervention can reasonably accomplish, given how it works, and how much help the client is actually receiving. By going beyond idealistic expectations that everything might change, we were able to focus on those domains that the intervention, adult day care, is likely to affect. Those targeted domains can become part of an assessment, which then, as this example shows, can provide valuable outcome data about the effectiveness of the intervention.

## Issues in Selection of a Caregiver Assessment Battery

One of the major issues that programs face in the selection of assessment instruments is whether to use an established measure or one that has been developed and tailored specifically for the program. Each approach has advantages and disadvantages.

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## Established Measures

**Advantages.** Established measures have been shown to have reliability and validity, and in some cases population norms are available. Reliability refers both to internal consistency, that is, that the measure assesses one dimension or construct, and not several constructs, and to short-term stability of the responses, that is, that what a caregiver answers today would be consistent with the responses that same person gives tomorrow. Validity is evidence that the measure assesses the intended construct and not a different construct. Although there are many technical ways of assessing validity, one of the most important and straightforward is to evaluate the face validity, that is, do the items reflect content consistent with the construct that we want to assess. For that purpose, it is essential to read the items carefully, and not just assume that the title represents accurately the underlying construct. We have seen that the term “burden” is used in many different ways; it is not unusual to find considerable discrepancy for other constructs, too, between what the measure is supposed to assess and the actual content of the items.

Some measures may also provide population norms or clinical cut-offs useful for deciding which people receive which services. Those kinds of norms, however, are still fairly rare and may not be useful if applied to a very different population. The obvious example would be if the norms were established on a predominantly white, middle class population, and the program designing the assessment instrument served a poor and racially diverse population. The established cut-off score would probably not be of much use in that case.

**Disadvantages.** Established measures also have drawbacks. These measures have been developed for purposes other than the type of assessment a program or service may want to conduct and may be too long or include dimensions that are not relevant. There is no gold standard for assessment measures that applies to every context. One alternative is to select parts of an instrument. There may, in fact, be information that justifies use of a short-form, or of a component of a larger, multidimensional assessment instrument. If no prior work has used these abbreviated forms, a psychometric evaluation of the new version would be useful, possibly in partnership with a researcher at a nearby university.

## Ad-Hoc, Tailored Measures

Another alternative is to construct a new ad-hoc measure that is tailored to the specific needs and purposes of the program. The drawback of this approach is that while it seems like an easy task to construct a few questions, it actually can take considerable time to write items that are interpreted clearly by the intended clients,

that are not leading or biased, and that reliably and validly assess the intended domain. Many of the ad-hoc measures I have reviewed have been poorly worded and constructed and did not yield helpful information. In other words, while these measures were on the right track in identifying information that would be most useful to the program, they needed more refinement. Again, a partnership with a researcher who could help develop the instrument could be productive.

## Systematic Administration

Whether using an ad-hoc or established measure, a critical point is to administer the battery in a systematic way to all clients. There should be a set of procedures

Whether using an ad-hoc or established measure, a critical point is to administer the battery in a systematic way to all clients.

for how the assessment is administered, and that should be followed as closely as possible. That means not skipping items that should be asked, changing the wording of items, skipping around in the instrument or other deviation from a basic protocol. I have often found that inexperienced clinicians want to take short-cuts or make decisions based on initial impressions that

parts of a battery are not relevant. These short-cuts often lead to clinical errors. Being systematic helps build up clinical understanding of clients and allows practitioners to make better, more insightful judgments.

## Cultural Relevance and Appropriateness

One other important consideration is that assessment instruments need to be culturally relevant and appropriate (Geron, 1997). We cannot assume that the wording of items, or even how a construct is operationalized, translates to minority groups. Despite the recognition of the importance of diversity in our society, and

Assessment instruments need to be culturally relevant and appropriate.

the growing diversity of the older population, little attention has been given to the need for specific modifications of wording of instruments or to the use of culturally relevant constructs and wording in assessments with particular groups. Increasingly,

research has been including more diverse populations, but finding tests of the specific construct of interest for a given population may still be difficult. Under these circumstances, it is possible to conduct preliminary tests of any instrument, getting feedback from participants as well as clinicians familiar with the culture. Translation from English to another language adds another level of complexity. Getting the right dialect of languages such as Spanish and Chinese is also important.

These complexities should not prevent the use of a structured assessment with minority populations. I have heard people say in a blanket way that it is not appropriate to do assessments with this or that group, but in both my clinical and research work, I have always found that the families from diverse groups with whom I have worked have appreciated the opportunity to give their views in response to a structured interview. The key is treating people with respect. The more we learn about the cultural background of a particular group, the better we will be able to do that, as well as to learn how to tailor the assessment to specific cultural issues relevant to caregiving.

## No Simple Formula to Choose Tools

There is, in the end, no simple formula to determine the optimal set of assessment tools. The stress process model and similar theoretical perspectives provide a broad template and examples of standardized measures for key domains, but programs need to tailor these assessments to their own specific needs. Consultation with experienced clinicians and researchers will help to identify the best approaches. The search for optimal measures will necessarily encounter the gap that exists between research and practice. Research measures often are not constructed with a clinical setting or clinical problem in mind. A research measure will not be available for every need, or those available may not fit the needs or questions raised by a given program.

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## Practical Issues in Assessing Caregivers

How staff implements an assessment battery will determine its effectiveness. Clinicians not familiar with using a structured approach to assessment are often reluctant to follow a protocol, or to ask more than a few structured, informational questions. They are concerned that the number of questions will make it difficult to establish rapport or will seem intrusive and discourage the client or caregiver from seeking further help.

How staff implements an assessment battery will determine its effectiveness.

These concerns represent a lack of familiarity with using structured assessments. Although the assessment is systematic and thorough, questions need not be asked in a stilted manner. The assessor can adopt a conversational tone and follow up important digressions. Paradoxically, an assessment battery can be used to keep overly digressive clients focused. It is possible to say to these clients that there are a lot of questions to go through, and that they will have time at the end to discuss issues that are not covered sufficiently.

Another advantage of a structured assessment is that it helps the clinician cover all the relevant areas. It is all-too-easy to get distracted by an interesting story or to follow digressions and not to gather all the information needed to begin treatment.

## Conclusions

The implications of research for assessment of caregivers are straightforward and include:

1. Research shows that caregivers are at high risk for a variety of adverse consequences of caregiving and are in need of services to reduce that risk.
2. Clinical experience demonstrates that caregivers are integrally involved in defining caregiving problems and need to be part of the solution.
3. Extensive evidence shows that caregiving stress is a multidimensional

**R**esearch shows that caregivers are at high risk for a variety of adverse consequences of caregiving and are in need of services to reduce that risk.

process, with each dimension having only low to moderate associations with other dimensions. Thus, we need to assess an array of components of the stress process to understand

caregivers' experiences and outcomes. Not every dimension needs to be assessed in every situation. A program or agency needs to consider which dimensions are most relevant to its clients and goals.

4. Structured assessments can be useful in clarifying a program's goals and in providing evidence of effectiveness.
5. Although some providers are reluctant to conduct a structured assessment, most clients will accept a focused instrument and it will lead to better identification of needs for services.

## Recommendations for the Future

Research can contribute to the development of assessment for caregivers in some key ways:

1. Research can refine measures and determine their psychometric properties.
2. Research can evaluate the acceptability of assessment instruments with clients, as well as gain useful information on how to modify instruments with those clients.
3. Findings from the assessment battery can be used to create a profile of caregivers served and their needs and functioning.
4. Research can help programs develop ongoing evaluations of implementation and effectiveness. Basic questions include whether the services implemented match the initial needs identified by the assessment and whether the immediate goals of the program are met in terms of the amount of service provided and the proximal impact on caregivers.

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## References

- Aneshensel, C., Pearlin, L., Mullan, J., Zarit, S.H., & Whitlatch, C.J. (1995). *Profiles in caregiving: The unexpected career*. New York: Academic Press.
- Anthony-Bergstone, C.R. Zarit, S.H., & Gatz, M. (1988). Symptoms of psychological distress among caregivers of dementia patients. *Psychology and Aging, 3*, 245-248.
- Brodaty, H., Green, A., Banerjee, S., Mittelman, M., Schulz, R., Whitehouse, P., Harvey, R., Powell, M., Prince, M., Rios, D., & Zarit, S. (2002). Towards harmonisation of caregiver outcome measures. *Brain Aging, 2*, 3-12.
- Coppel, D. B., Burton, C., Becker, J., & Fiore, J. (1985). Relationships of cognitions associated with coping reactions to depression in spousal caregivers of Alzheimer's disease patients. *Cognitive Therapy and Research, 9*, 253-266.

- Deeken, J. F., Taylor, K. L., Mangan, P., Yabroff, K. R., & Ingham, J. M. (2003). Care for the caregivers: A review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *Journal of Pain and Symptom Management, 26*(4), 922-953.
- Drinka, T. J., Smith, J., & Drinka, P. J. (1987). Correlates of depression and burden for informal caregivers of patients in a geriatrics referral clinic. *Journal of the American Geriatrics Society, 35*, 522-525.
- Eisdorfer, C., Czaja, S. J., Loewenstein, D.A., Rubert, M. P., Arguelles, S., Mitrani, V.B., & Szapocznik J. (2003). The effect of a family therapy and technology-based intervention on caregiver depression. *Gerontologist, 43*, 521-531.
- Family Caregiver Alliance (2002). *Selected caregiver assessment measures: A resource inventory for practitioners*. San Francisco, CA: National Center on Caregiving.
- Feinberg, L. F. (2004). The state of the art of caregiver assessment. *Generations, 27*, 24-32.
- Gallagher, D., Rose, J., Rivera, P. Lovett, S., & Thompson, L.W. (1989). Prevalence of depression in family caregivers. *The Gerontologist, 29*(4), 449-456.
- Gaugler, J. E., Edwards, A. B., Femia, E. E., Zarit, S. H., Stephens, M. A. P., Townsend, A., & Greene, R. (2000). Predictors of institutionalization of cognitively impaired elders: Family help and the timing of placement. *Journal of Gerontology: Psychological Science, 55B*, P247-P255.
- Geron, S. M. (1997). Taking the measure of assessment. *Generations, Spring*, 5-9.
- Guberman, N., Nicholas, E., Nolan, M., Rembicki, D., Lundh, U., & Keefe, J. (2003). Impacts on practitioners of using research-based carer assessment tools: Experiences from the UK, Canada, and Sweden, with insights from Australia. *Health and Social Care in the Community, 11*(4), 345-355.
- Kanfer, F. H. & Saslow, G. (1965). Behavioral analysis: An alternative to diagnostic classification. *Archives of General Psychiatry, 12*, 529-538.
- Kinney, J. M. & Stephens, M.A. (1989). Hassles and uplifts of giving care to a family member with dementia. *Psychology of Aging, 4*(4), 402-408.
- Lawton, M. P. Brody, E., & Saperstein, A.R. (1989). A controlled study of respite services for caregivers of Alzheimer's patients. *Gerontologist, 29*, 8-16.
- Lazarus, R. S. & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- MaloneBeach, E. E. & Zarit, S. H. (1995). Dimensions of social support and social conflict as predictors of caregiver depression. *International Psychogeriatrics, 7*, 39-50

- Max, W., Webber, P., & Fox, P. (1995). Alzheimer's disease: The unpaid burden of caring. *Journal of Aging and Health, 7*, 179-199.
- Mittelman, M.S., Ferris, S.H., Shulman, E., Steinberg, G., Ambinder, A., Mackel, J., & Cohen, J. (1995). A comprehensive support program: Effect on depression in spouse-caregivers of AD patients. *Gerontologist, 35*, 792-802.
- Mittelman, M.S., Ferris, S.H., Shulman, E., Steinberg, G., & Levin, B. (1996). A family intervention to delay nursing home placement of patients with Alzheimer's disease. *Journal of the American Medical Association, 276*, 1725-1731.
- Mittelman, M. S., Roth, D.L., Coon, D.W., & Haley, W.E. (2004). Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with Alzheimer's disease. *American Journal of Psychiatry, 161*, 850-856.
- Nolan, M., Grant, G., & Keady, J. (1995). CAMI: A basis for assessment and support with family carers. *British Journal of Nursing, 1*(3), 822-826.
- Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist, 30*(5), 583-594.
- Pruchno, R. A., Kleban, M. H., Michaels, J. E., & Dempsey, N. P. (1990). Mental and physical health of caregiving spouses: Development of a causal model. *Journal of Gerontology, 45*, 192-199.
- Radloff, L.S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385-401.
- Rapp, S. R. & Chao, D. (2000). Appraisals of strain and of gain: Effects on psychological wellbeing of caregivers of dementia patients. *Aging and Mental Health, 4*(2), 142-147.
- Redinbaugh, E. M., MacCallum, R. C., & Kiecolt-Glaser, J. K. (1995). Recurrent syndromal depression in caregivers. *Psychology and Aging, 10*, 358-368.
- Schulz, R. & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association, 282*, 2215-2219.
- Schulz, R., Burgio, L., Burns, R., Eisdorfer, C., Gallagher-Thompson, D., Gitlin, L. N., & Mahoney, D. F. (2003). Resources for enhancing Alzheimer's caregiver health (REACH): Overview, site-specific outcomes and future directions. *Gerontologist, 43*, 514-520.
- Schulz, R., O'Brien, A. T., Bookwala, J., & Fleissner, K. (1995). Psychiatric and physical morbidity effects of Alzheimer's disease caregiving: Prevalence, correlates and causes. *The Gerontologist, 35*, 771-791.

- Schulz, R., Visintainer, P., & Williamson, G.M. (1990). Psychiatric and physical morbidity effects of caregiving. *Journal of Gerontology*, *45*, 181-191.
- Schulz, R., Wrosch, C., & Heckhausen J. (2003). The life-span theory of control: Issues and evidence. In S. Zarit, L. Pearlin, & K.W. Schaie (Eds.) *Personal control in social and life course contexts* (pp. 233-262). NY: Springer.
- Semple, S.J. (1992). Conflict in Alzheimer's caregiving families: Its dimensions and consequences. *Gerontologist*, *32*, 648-655.
- Skaff, M. M. & Pearlin, L. I. (1992). Caregiving: Role engulfment and the loss of self. *Gerontologist*, *5*, 656-64.
- Stephens, M. A., Townsend, A. L., Martire, L. M., & Druley, J. A. (2001). Balancing parent care with other roles: Interrole conflict of adult daughter caregivers. *Journal of Gerontology B: Psychological Sciences and Social Sciences*, *56*(1), P24-34.
- Teri, L., Truax, P., Logsdon, R., Uomoto, J., Zarit, S.H., & Vitaliano, P.P. (1992). Assessment of behavioral problems in dementia: The revised memory and behavior problems checklist. *Psychology and Aging*, *7*, 622-631.
- Thompson, E. H. & Doll, W. (1982). The burden of families coping with the mentally ill: An invisible crisis. *Family Relations*, *31*, 379-388.
- Vitaliano, P. P., Maiuro, R. D., Ochs, H., & Russo, I. (1989). A model of burden in caregivers of DAT patients. In E. Light & B. Lebowitz (Eds.), *Alzheimer's disease: A report of progress in research* (pp. 267-291). Washington, DC: U.S. Government Printing Office.
- Vitaliano P.P., Russo J., Young H.M., Becker J., & Maiuro R.D., (1991). The Screen for Caregiver Burden. *The Gerontologist*, *31*, 76-83.
- Whitlatch, C. J., Zarit, S. H., & von Eye, A. (1991). Efficacy of interventions with caregivers: A reanalysis. *Gerontologist*, *31*, 9-14.
- Wright, L.K., Clipp, E.C., & George, L.K. (1993). Health consequences of caregiver stress. *Medicine, Exercise, Nutrition and Health*, *2*, 181-195.
- Yates, M.E., Tennstedt, S. & Chang, B.H. (1999). Contributors to and mediators of psychological well-being for informal caregivers. *Journal of Gerontology: Psychological Sciences*, *54*, P12-22.
- Zarit, S. H. & Leitsch, S. A. (2001). Developing and evaluating community based intervention programs for Alzheimer's patients and their caregivers. *Aging and Mental Health*, *5*(Suppl), S84-S98.
- Zarit, S. H., Orr, N. K., & Zarit, J. M. (1985). *The hidden victims of Alzheimer's Disease: Families under stress*. New York: NYU Press.

- Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, 20, 649-655.
- Zarit, S. H., Stephens, M.A.P., Townsend, A., & Greene, R. (1998). Stress reduction for family caregivers: Effects of day care use. *Journal of Gerontology: Social Sciences*, 53B, S267-S277.
- Zarit, S. H., Stephens, M. A. P., Townsend, A., Greene, R., & Leitsch, S. A. (1999). Patterns of adult day service use by family caregivers: A comparison of brief versus sustained use. *Family Relations*, 48, 355-361.
- Zarit, S. H. & Zarit, J. M. (1998). *Mental disorders in older adults: Fundamentals of assessment and treatment*. New York: Guilford.

# Assessment of Family Caregivers: A Practice Perspective

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## Abstract

The need to assess caregivers systematically is becoming a practice imperative if we are to assure their well-being and ultimately, that of the people for whom they care. The purpose of this paper is to synthesize, from a practice perspective, the state of the art relative to assessment of family and informal caregivers of older people and adults with disabilities. In this paper the key practice issues are explored, beginning with questions of values and moving to the what, how and where of caregiver assessment; the links between assessment, interventions and outcomes; implementation concerns and strategies; and finally, questions for further research.



## Introduction

Family caregivers are assuming between 70 and 80 percent of care to disabled and ill people (Stone, 2000; Thompson, 2004) and saving society \$257 billion dollars per year in unpaid labor (Arno, 2002).

The need to assess caregivers systematically is becoming a practice imperative if we are to assure their well-being and ultimately, that of the people for whom they care.

Still, they do so with little recognition or support from policy makers, health care practitioners and service providers. The need to assess caregivers systematically is becoming a practice imperative if we are to assure their well-being and ultimately, that of the people for whom they care.

Caregivers' status with regard to service agencies is particularly ambiguous. Generally, caregivers are not officially clients of the health and social service system: files are opened in the name of the care recipient. Hospital, home care and long-term care practitioners' evaluations and interventions rarely consider caregivers' needs (Levine, Reinhard, Feinberg, Albert & Hart, 2004; Guberman & Maheu, 2002). The care recipient's characteristics, rather than an evaluation of the caregiver's needs determines services offered to caregivers, and support offered without assessment is most often on a "one size fits all" basis. For ex-

ample, programs such as respite or support groups for caregivers of persons suffering with Alzheimer's disease are set up in the hopes that they will correspond to caregivers' needs. Research shows that this often does not occur.

We cannot afford to maintain the current situation without seriously compromising the well-being of millions of Americans. Despite the many rewarding aspects of caregiving (Kramer, 1997), research shows that caregivers face many issues in adjusting to the caregiving role. These include: work overload; role conflict and overload due to multiple caregiver responsibilities; permanent state of worry given the unpredictable situation; serious restrictions imposed by the demands of caregiving, which can lead to a feeling of entrapment; financial worries from medical expenses, indirect expenses and loss of income; and legal problems around mental incompetence, living wills and inheritance issues (Dhopper, 1991; Guberman, Maheu & Maillé, 1991; 1993; Keefe & Fancey, 1997). Those that quit their jobs diminish their opportunity for future employment and reduce their pension incomes (Neal, Chapman, Ingersoll-Dayton & Emlen, 1993; Scharlach et al., 1991; U.S. Social Security Administration, 2002; Wakabayashi & Donato, 2004). Many studies document how caregiving compromises caregivers' physical and mental health (Canuscio, Jones, Kawachi, Colditz, Berkman & Rimme, 2002; Kiecolt-Glaser & Glaser, 2003; Lee, Colditz, Berkman, & Kawachi, 2003; Schulz, O'Brien, Bookwala & Fleissner, 1995; Schulz & Beach, 1999; Yee & Schulz, 2000; Zarit & Edwards, 1996). If the levels of stress, distress and illness found in caregivers were found in any other "profession," health agencies and workers' compensation boards would undoubtedly be waging major prevention campaigns, yet these impacts on caregivers are barely addressed in public policy.

## Purpose of Paper

The purpose of this paper is to synthesize, from a practice perspective, the state of the art relative to assessment of informal and family caregivers of the elderly and adults with disabilities. In this paper the key practice issues are explored, beginning with questions of values and moving to the what, how and where of caregiver assessment; the links between assessment, interventions and outcomes; implementation concerns and strategies; and questions for further research.

## Methodology

This paper is based on a literature review and interviews with key informants experienced in caregiver assessment. Caregiver assessment is mandated in the United Kingdom (UK), so the literature reflects more on the British than the North Ameri-

can experience. To compensate, the majority of key informant interviews focused on North America.

States highlighted in this document (California, New Jersey, Utah) were chosen because of their experience in at least one of the home and community-based (HCBS) programs with a specific caregiver assessment tool. Some states (California, New Jersey, Pennsylvania and Washington) have well-established caregiver support programs that pre-date the enactment of the Older American Act's National Family Caregiver Support Program (NFCSP). In California, uniform assessment of family caregivers' needs has occurred since 1988 through the state-funded Caregiver Resource Center (CRC) network. For most states, however, policy attention to caregivers has emerged only recently and because of the NFCSP (Feinberg & Newman, 2004). No state has evaluated the outcomes of assessing caregivers.

## Why Assess Caregivers?

From a practice perspective, many reasons justify caregiver assessment. A better understanding of caregivers' circumstances helps to evaluate risks to their well-being and the caregiving situation (Pickard, 2004), to reduce burden (New Zealand Guidelines Group, 2003) and to counter the negative consequences of caregiving (Gaugler, Kane & Langlois, 2000). The Southern Caregiver Resource Center in San Diego (one of California's 11 CRCs) found that learning about the caregiving situation and caregiver needs through a systematic caregiver assessment process enabled staff to decrease crises and ensure that caregivers could provide a safe environment for the care recipient and themselves (L. Van Tilburg, interview, March 18, 2005)<sup>1</sup>. Effective assessment can be the key to getting maximum value for caregivers from limited resources (Audit Commission, 2004). Spending more time to look at caregiver circumstances and options, as well as equipping them to make informed choices, may be more effective than a "quick service fix" (Ellis, 1993). In Utah, since the passage of the NFCSP in 2000, an assessment process has helped draw a better picture of the caregiving situation than previously, when caregivers called in for a specific service (respite). With a home visit assessment, case managers can see other environmental factors and issues to broaden the scope of services offered (S. Yudell, interview, March 31, 2005). While research has clearly demonstrated that no single intervention works for all, the NFCSP, without assessment, gives no guidance to case managers about how best to help caregivers (R. Montgomery, interview, April 1, 2005). Assessment enables one to know when, why and how to use the different interventions.

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<sup>1</sup> Interviews with key informants were completed between March 18 and April 8, 2005. See references for complete information.

In addition, assessment can identify low or no cost ways of helping the caregiver (e.g., information, referral, advice, sympathetic ear).

Assessments provide practitioners a standardized format to get specific information and orient the dialogue with caregivers (C. Furman, interview, March 30, 2005). Assessment also leads to practitioner recognition that caregivers' needs may differ from those of the care recipient, helping them plan support services accordingly (Feinberg, 2004). Several authors point to improved care for the care recipient as a reason for assessing and addressing caregiver needs (Feinberg, 2004; Maddock, Kilner & Isam, 1998).

Assessments provide practitioners a standardized format to get specific information and orient the dialogue with caregivers.

## What Is Caregiver Assessment?

Wide-ranging definitions of caregiver assessment are used in practice settings, including:

- ◆ A process to determine eligibility for services;
- ◆ A process of information gathering that describes a caregiving situation, identifies problems or concerns that may be addressed by intervention and provides a rationale for developing a care plan to improve the caregiving situation (Bass, 2001);
- ◆ A purposive conversation to uncover hidden needs, to gain insights into the complexities in the lives of caregivers and to plan appropriately (Victorian Order of Nurses, 2004);
- ◆ An interactive, personalized, contextually determined helping relationship aimed at the provision of effective support of caregiver and care recipient within the limits of available resources and which promotes caregivers' well-being and freedom to have a life of their own (Borgermans, Nolan & Philp, 2001).

How assessment is conceptualized depends much on one's beliefs about the role of family in care to disabled and ill people and the respective responsibilities of caregivers and services. Research reveals that policy makers and practitioners see caregivers in different lights, sometimes as co-clients with the care recipient, sometimes as resources which must be mobilized and educated to meet the needs of the care recipient and to relieve over-burdened services, and occasionally as co-workers or partners (Maheu & Guberman, 1998; Twigg, 1988; Twigg & Atkins, 1994). On one hand some believe that care is mainly a family responsibility with services acting only when

and if families are unable to pursue this role. Others believe that caregivers have the right to take up or decide not to take up, to continue or to end caring. The first belief leads to assessments aimed at determining who is at the breaking-point in order to put short-term, often intensive, services into place to maintain caregivers in their role for as long as possible; the second view leads to assessments more focused on the caregiver's perspective and needs.

Another way to characterize these differing practice perspectives is “service-oriented” versus “user-centered” caregiver assessment (Richards, 2000). The former takes a gate-keeper approach, focused on protecting against the “woodwork syndrome” which holds that large numbers of caregivers would “come out of the woodwork” to claim services if they were widely offered. Thus, service-oriented assessments are designed to ensure that services are rationally allocated based on eligibility criteria (e.g., high levels of burden, depression or other measures of caregiver distress). They tend to be prescriptive, administered by professionals, often based on checklists, and rarely take into account the caregiver's perceptions and expectations. Such assessments may result in a denial of services to a caregiver deemed too competent, too healthy or having too many financial or other resources to deserve support.

In contrast, the user-driven approach embraces the view that the “woodwork” concern is groundless, as most caregivers seem to want few services. Nolan (interview, March 24, 2005) expresses this view: “Caregivers are more modest than excessive in their demands for services after assessment.” Proponents of this perspective say some of the most cost-effective care packages result when caregivers are central to the package and offered sufficient supports to enhance their well-being and maintain their own health (Carers UK, 2002). Thus, the user-oriented assessment, seen as the first stage of intervention, emphasizes the assessment process itself. Aimed at developing an individualized, contextualized understanding of the person's needs, this type of assessment does not use predetermined closed questions and makes no assumptions about the caregiver's willingness to undertake a range of tasks or to continue caring at the current level. It recognizes that the stress of caring is highly mediated through factors particular to the individual, with the outcomes of intervention being defined at least in part from the caregiver's perspective (Qureshi, 2000; Twigg, 1993). Thus, it focuses on raising caregiver awareness of their situation, facilitating discussion and interaction between family and professionals to help both partners gain a complete a picture of the caregiving situation in order to devise the most appropriate and timely kinds of support (Lundh & Nolan, 2003).

## Content of Caregiver Assessment Tools

Consensus on what to include in caregiver assessment tools is growing (Feinberg, 2004; Fancey & Keefe, 1999). Most tools, reflecting recognition of the complexity of caregiving, use a combination of caregiver-specific (burden) and generic (health status) dimensions. Typically seen are these themes: type and frequency of care provision, such as help for activities of daily living and instrumental activities of daily living (ADLs and IADLs); other responsibilities that may interfere with caregiving, such as employment; informal support; formal service needs; personal health, often as a barrier to providing care; burden and emotional reactions to giving care; caregiver ability to continue with care; basic demographic and contextual information, such as living arrangements and ethnicity. Some tools also include financial and legal information needs (e.g., out-of-pocket expenses, emergency contacts, knowledge and use of advance directives, guardianship and other legal planning tools); information about specific tasks; and information about housing and home environment.

Feinberg (2004) and others (M. Nolan, interview, March 24, 2005; Guberman et al., 2001) point to some areas that are often neglected: actual tasks performed beyond personal care; quality of care provided; skills necessary to provide the care; values and preferences of the caregiver and the care recipient; positive aspects of caregiving; the history, quality and potential stresses of the care recipient-caregiver relationship; the relationship with other members of the family; crisis and future planning; relationships with formal providers and access to information. According to Nolan (interview, March 24, 2005) questions about the caregiver's willingness and ability to assume or pursue caregiving should be central to any assessment. Caregivers should know exactly what they are getting into and what is involved, and should they agree to go forward, assessment should determine what skills and support they need to do so.

## What Should Trigger a Caregiver Assessment? When Should It Occur?

Ideally, all caregivers who come into contact with the health and social service systems should be assessed routinely as early as possible to involve them in care planning and to identify their own needs. Any change in the acute health status of a person should act as an assessment trigger, particularly before discharge from hospital, rehabilitation facility and nursing home. In this approach, caregiver assessment is contingent on the care recipient's qualifying for and accepting formal services, thus denying many caregivers access. In Sweden, a project currently underway is sending

simple self-administered assessment to all potential caregivers. Those who identify issues they would like to address then receive a face-to-face assessment.

When intake or discharge of a care recipient triggers caregiver assessment, a short, rapid screening tool may be administered, with those scoring high then being more fully assessed. A study conducted by Guberman and colleagues (2001), as well as British experiences suggest that caregiver assessment, at least in agencies that provide services to the person requiring care, should take place after the care recipient's services are in place, because most caregivers are too focused on the care recipient to think about their own situation and needs prior to then. The care trajectory, the care situation and caregiver needs all change over time, calling for regular reassessment to be part of assessment practice. Generally, a review is recommended every four to six months or when caregivers say their situation or needs have changed.

## Who Assesses Caregivers? Who Should Be Involved in the Caregiver Assessment?

Most often, professional social workers, and sometimes nurses or rehabilitation professionals, perform caregiver assessments. As to who participates in the assessment, some focus on the self-identified caregiver, some on the “primary caregiver” (who can be more than one person), and others on the entire family system (Feinberg, 2004). Having the same professional assess both care recipient and caregiver, who may have conflicting interests, raises an ethical issue. Assessments may be done separately if more than one person is involved.

## Where Should a Caregiver Assessment Take Place?

Ideally, assessment should take place in the caregiver's home or another place where the care situation can be discussed freely and openly with the assessor (Guberman, Keefe, Fancey, Nahmiash & Barylak, 2001; Robinson & Williams, 2003; Stanley, 1999). Substitute care provisions may be necessary to free up the caregiver for the assessment. Stanley (1999), shadowed assessors, noting that when assessments took place in the presence of the care recipient, the caregiver was not able to speak about areas where their interests did not coincide. Home assessments have been shown to be better than clinic-based assessments at identifying potentially serious caregiver issues (Ramsdell, Jackson, Guy & Renvall, 2004).

## How Do the Caregiver Assessment, the Care Recipient's Assessment and the Care Plan Link Up?

A caregiver assessment may be part of a state's uniform assessment tool for its Medicaid waiver or other home and community-based programs, as in the cases of Washington State, Minnesota and Pennsylvania. In some cases, such as in Minnesota, the caregiver component is optional and left to the discretion of the assessor. Another, still rare, approach is for state service systems to use a separate assessment tool aimed specifically at caregivers (e.g., California Caregiver Resource Centers' Uniform Assessment Tool, Utah Caregiver Support Program Assessment).

Caregiver sections in an overall tool aimed mainly at the care recipient often do not link to an intervention plan for the caregiver, even though assessors may learn that the caregiver is stressed, burdened or otherwise in difficulty. Most combined tools have a distinct "caregiver as resource" focus, rather than attempting to understand the caregiver's perspective and needs.

Combining the caregiver and care recipient assessment may overcome staff and caregiver resistance to "yet another assessment form," but assessing two (or more) individuals with one tool raises many questions. Is it possible to meet with caregivers alone to answer the questions that concern them? Can the assessor gain a full understanding of the caregiver's situation, given the limited areas touched upon? What weight will be given to the caregiver's reality in determining priorities for services? Can an assessment indicating high levels of need on the part of the caregiver lead to services even if the care recipient's assessment does not? Caregiver sections in an overall tool aimed mainly at the care recipient often do not link to an intervention plan for the caregiver, even though assessors may learn that the caregiver is stressed, burdened or otherwise in difficulty. Most combined tools have a distinct "caregiver as resource" focus, rather than attempting to understand the caregiver's perspective and needs.

In both approaches, the link between assessment and ensuing care plans are not always obvious, especially when using standardized measures. For example, high scores on depression or burden scales, do not necessarily point clearly to appropriate interventions. An assessment tool under development (R. Montgomery, interview, April 1, 2005) includes protocols on what to do with the information gathered. The tool will elicit where the caregiver is in the caregiving process and the pressure points so to determine the fit with appropriate services. The C.A.R.E. Tool (Guberman, et al., 2001), a comprehensive caregiver-led assessment tool, also enables assessors to indicate the key areas of concern and immediately link these to services or resources which address the concern.<sup>2</sup>

<sup>2</sup> See Appendix 1 (page 57), which presents a case study demonstrating how assessment links to intervention and caregiver outcomes.

## How Should Assessors Be Trained?

According to the Audit Commission Report (2004) from the UK, assessors need a particular mindset and skill set to undertake caregiver assessment, especially to promote the caregiver-as-partner approach. Training should address both aware-

Caregivers appreciate being informed of the purpose of the assessment, having a face-to-face encounter centered on their definition of their needs, being shown that they are valued and recognized as experts and having the assessment form be a guide, not the center of the process.

ness of caregivers and assessment itself. Caregiver awareness training, the report suggests, should be part of the program curriculum for all health care workers (e.g., doctors, nurses, social workers). Others point to further areas for training: interviewing skills; knowledge of hu-

man behavior; family and caregiving dynamics; aging and disability issues; awareness of resources and options available to caregivers in the community; anti-discrimination training; and skills at working with interpreters (Geron, 1997; Ellis, 1993).

Van Tilburg (interview, March 18, 2005) feels assessors need specific skills to keep on track, give the caregiver room to tell her/his story and answer the assessment questions. She recommends that practitioners be trained with a standardized assessment tool to give them a clear direction and focus for intervention and that the clinical relevance of each question be clear so assessors know what to probe for in the conversation around each question.

Training and supervision should be ongoing. Seddon and Robinson (2001) suggest that assessors be adequately supported to keep abreast of policy and practice developments and stay up to date in their community-resources knowledge.

Studies on what caregivers consider to be good assessment practice provide other elements to be included in training (Qureshi, Arksey & Nicholas, 2003). Caregivers appreciate being informed of the purpose of the assessment, having a face-to-face encounter centered on their definition of their needs, being shown that they are valued and recognized as experts and having the assessment form be a guide, not the center of the process.

## What Outcomes Does Caregiver Assessment Affect?

Caregiver assessment may impact caregivers, care recipients, practitioners, practice and system development. Nicholas (2003) suggests that for caregivers, the outcomes of caregiver assessment should be: freedom to have a life of one's own, maintaining one's own health and well-being, preventing social isolation, providing

peace of mind and providing appropriate support if one chooses to become a caregiver. Studies have documented the therapeutic impact of assessment that takes a caregiver's situation seriously. Experiences in the UK and Australia point to numerous outcomes related to caregiver assessment: recognition of their role, a chance to talk through their issues and consider their own needs, self-understanding of their situation, feelings and the caring role, new insights into why they are caring and what they have achieved, expression of bottled-up emotions, permission to talk about difficult and delicate subjects, validation of their feelings, acceptance of support, peace of mind in knowing how to make contact in the future, information and referral information, a sense of shared responsibility, increased confidence to take up services, confirmation as people of value, recognition and validation (Lundh & Nolan, 2003; Carers UK, 2002; Hepworth, 2003; Maddock et al., 1998).

Assessment leads to a concrete plan that helps move caregivers from point A to point B, reducing levels of stress and burden and increasing their knowledge, competency and general mastery of their role as a caregiver.

According to the practitioners who were interviewed (L. Van Tilburg, March 18, 2005; C. Furman, March 30, 2005), assessment leads to a concrete plan that helps move caregivers from point A to point B, reducing levels of stress and burden and increasing their knowledge, competency and general mastery of their role as a caregiver. Whether a one-hour phone interview or a three-hour home visit, assessment makes a difference in the caregiver's world. The services the caregiver taps into as a result make a difference in their ability to cope.

Few documented studies systematically explore the impact of assessment in and of itself, in terms of outcomes to well-being. Research on the C.A.R.E. tool by Keefe and colleagues in Canada is undertaking this challenge. In their carer needs assessment trial, Maddock and colleagues (1998) found that one month after assessment, caregivers (n=51) stated they were more able to continue in their role because of the assistance/support provided by nurses (67%), and had higher perceived levels of social support (58%), decreased information needs (46%) and decreased levels of strain (50%). A pilot project in Maine suggests that caregivers screened by primary health professionals and referred to their local Area Agency on Aging's (AAA) caregiver services have increased knowledge levels and decreased levels of depression at six months after service initiation, despite increased task frequency and difficulty (Kaye, Turner, Butler, Downey & Cotton, 2003).

Research on the impact of caregiver assessment on the care recipient also is lacking. Three practitioners interviewed for this paper (L. Van Tilburg, March 18, 2005; C. Furman, March 30, 2005; S. Yudell, March 31, 2005) believe the care recipi-

ent benefits from the caregiver's assessment, particularly when it leads to decreasing caregiver stress and increasing caregiver confidence and skills in behavior management and communication.

Caregiver assessments raise practitioner awareness of caregiving situations and change taken-for-granted assumptions. They provide insights about what it means to be a caregiver and the daily realities of care; enhance understanding of the complexities of caregiving; challenge existing perceptions/expectations; enable a better response to caregiver needs, going beyond symptoms to understanding the under-

**F**ocusing on family caregivers changes the notion of the client within the health and social service systems and transforms the relationship between caregivers and the system.

lying causes of caregiver difficulties; and release innate creativity (Guberman et al., 2003; Lundh & Nolan, 2003; Maddock et al., 1998; Nicholas, 2003).

Focusing on family caregivers changes the notion of the client within the health and social service systems and transforms the relationship between

caregivers and the system. It legitimizes caregivers' right to be heard, provides a rationale for directing services to caregivers, justifies practitioners' intervention strategies and highlights information that can contribute to future service development (Audit Commission, 2004; Guberman et al., 2003; Lundh & Nolan, 2003; Maddock et al., 1998). Assessment elicits a more accurate profile of caregiving situations and a clearer identification of caregiver needs that leads to the development of new services and resources to fill the gaps (Guberman et al., 2001; 2003; Nicholas, 2003).

In terms of long-term care systems development, the inclusion of systematic, uniform caregiver assessment throughout the myriad of home and community-based services can help to reduce fragmentation. Uniform, aggregated assessment information on caregivers can enable administrators to measure the impact of services on caregivers and provide data needed to support and drive decision-making (Feinberg, Newman, Gray, Kolb & Fox-Grage, 2004).

## Challenges to Implementation

To implement caregiver assessment in practice requires buy-in from all the stakeholders. Assessment must be part of a multi-dimensional approach to caregivers that sets out how agencies/governments are proposing to support them and clarifies underlying philosophies and caregiver status. Commitment from senior management, policymakers and funders toward caregivers and their assessment is essential for success (Maddock et al., 1998).

For example, are caregivers to be seen as resources to the system, with emphasis placed on training and educating them to take on more care activities? If so, services play a secondary role and intervention supplies only what they are unable to provide. Or are caregivers seen as potential clients of services and as potential partners in supporting people with disabilities in the community? This view would require a shift in thinking and practice. Many researchers and practitioners concur that getting assessors to see the caregiver as the client is the major challenge in implementing assessment and having a specific tool and training is key (Feinberg & Newman, 2004; C. Dennis, interview, April 8, 2005; S. Yudell, interview, March 31, 2005). “The caregiver as client model is great,” says Furman. “But I wouldn’t have said that two years ago because then my focus was completely on the patient... When I actually saw for myself what was happening in the home and the community, I realized that the caregiver is key to keeping everything going.”

For such a significant shift to take place, it must be an agency priority at all levels. Administrators and supervisors must be in full agreement to give front-line workers the necessary support. Administrative considerations include whether caregivers will have their own client records and the impact on current organizational and budgetary practices.

Several concerns lie behind practitioner resistance to caregiver assessment: excessive paperwork, lack of time due to care recipients’ already overwhelming needs, lack of resources to meet the assessed needs of caregivers and fear of intruding into caregiver’s time and privacy, including raising sensitive issues with which they are not prepared to deal.

The constraints of limited resources and the need to balance the interests of a range of stakeholders challenge practitioners. When resources are rare, practitioners feel powerless and find it easier not to make caregiver needs explicit (Nicholas, 2003). In the UK, the biggest factor determining how case managers approached caregiver assessment was caseload size (Audit Commission, 2004). The issue of time surfaces in almost all discussions of caregiver assessment. Practitioners see lengthy assessment tools as a waste of direct service time, especially if items are irrelevant for a particular caregiver or for available services (Bass, 2001). An assessment can and should take from 1½ to 2 hours although it need not be done in one meeting. Indeed, two or even three meetings with the caregiver may be preferable. The unpredictability of the situation often leads caregivers to reply differently about the stresses of caregiving from one day to the next (Guberman et al., 2001; Maddock, 1998). In actual practice situations, when assessors have the training to raise issues with the understanding that the caregiver has the power to decide whether or not to explore them, few caregivers feel assessment is too intrusive or time-consuming (Nicholas, 2003; Baxter, 2000; L. Van Tilburg, interview, March 18, 2005).

Generally, practitioner resistance must be faced head-on. Montgomery (interview, April 1, 2005) feels case managers will buy in when they understand why they are collecting the data and how it is used to advance the care plan. Bass (2001) suggests introducing flexibility into the process, including flexibility in the timing of full assessment and in the administration of the assessment tool. Others underscore the importance of educating staff to the benefits of assessing caregiver issues, to the options and services available and to their responsibility to respond to caregiver needs. Manageable caseloads and on-going supervision must back up training (Maddock et al., 1998; Audit Commission, 2004).

A further challenge to implementing caregiver assessment is identifying caregivers and mobilizing them for assessment. The terms “caregiver” and “assessment” may turn people away because they see themselves as family members, not as caregivers, and because the term assessment is interpreted as a process of passing judgment on their fitness to care rather than on their situation and their needs. Identifying caregivers also is daunting since this population constantly changes. In the UK, for example, more than one-third of caregivers cease to provide or begin assuming care in any one year (Hepworth, 2003). Even where assessment is mandated, an estimated half of caregivers are not known to service agencies (Audit Commission, 2004). The reasons, besides lack of awareness and self-identification as caregivers, include lack of knowledge of entitlement, ambiguity as to the outcomes of assessment and difficulty asking for help. The Audit Commission has proposed that primary care providers identify and refer caregivers and suggested that: (1) physicians distribute a letter to all potential caregivers addressing the issues and the right to assessment, (2) posters and leaflets be placed in GP’s offices, and (3) promotional activities be organized, such as Carers’ Week or Carers’ Rights Day.

The multi-cultural composition of the American population poses yet other implementation challenges, including the issues of language and cultural values around caregiving and service use. User-centered tools that allow caregivers to respond in a contextualized manner seem to work better with people from minority ethno-racial groups (Guberman et al., 2001; Hepworth, 2003), but research in this area is scarce. Specific strategies to encourage minority caregivers to self-identify and participate in assessment must be developed.

## What Further Research Is Needed?

Many questions surrounding caregiver assessment remain unanswered. First and foremost, does assessment, per se, pursued under real world conditions make a difference in caregiver well-being? Does it lead to lowered levels of burden, depression, etc.? A few controlled intervention studies positively link assessment, inter-

vention and outcome (Gitlin, Hauck, Dennis, & Winter, 2005; Hoskins, Coleman & McNeely, 2005; Mittelman, Roth, Coon & Haley, 2004). However, they may not be generalizable to the context of real practice when caregiver assessment and intervention is integrated into ongoing caseloads and overworked professionals. It would be interesting to evaluate, using a quasi-experimental design, the specific impact of assessment in practice settings, not only in terms of immediate outcomes for caregivers but also in terms of changes in services plans, relations between service providers and caregivers, and system development. Such research may lead us to affirm more confidently that the investment of time, money and human resources to perform caregiver assessment would lead to desired outcomes for caregivers.

Another question concerns the relative merits of the vast, and growing, array of caregiver assessment tools. A study comparing the efficiency, appropriateness and adaptability to everyday practice of these tools might be appropriate, bringing into play the benefits and drawbacks of standardized versus open-ended, caregiver-driven assessment and leading us back to the philosophy underlying assessment. The tool employed may turn out to be less important than the act of sitting down to hear and then act upon the caregiver's story.

Finally, we need further research to consolidate our knowledge of the appropriateness of different types of tools in different settings, and with different populations. What are the advantages and disadvantages of standardizing assessment and using a uniform caregiver tool across settings and disease groups? Certainly, minimal evidence available (Guberman et al., 2001) suggests that a comprehensive tool touching on the major elements of the caregiving experience can be employed appropriately with a vast array of caregivers (varying in age, relation to the care recipient, ethnic origin, level of involvement in care) caring for diverse groups of people (e.g., frail elderly and other adults with all types of physical, mental and cognitive disabilities). Is standardized assessment more helpful with caregivers who have fewer skills in understanding and negotiating the system, or at specific moments in the caregiving trajectory?

## Conclusion

Many caregivers are endangering their health and mental well-being, sacrificing their professional lives and economic futures, and, in some cases, dying, in order to care for ill and disabled friends and relatives (Schulz & Beach, 1999). They are making an invaluable contribution to American society. Can we remain blind to their situation? Can we continue to study and work with caregivers and document their realities but not intervene in a way that takes into account their own well-being?

Can we continue to study and work with caregivers and document their realities but not intervene in a way that takes into account their own well-being?

Assessment tools legitimize the right of practitioners to open the door to caregivers, to hear their stories and to determine service plans based on a full understanding of the global care situation, not just the needs and reality of the person needing care. An effective caregiver assessment tool enables practitioners to identify key areas of concern to the caregiver and to develop ways to respond creatively. Having a clear rationale, including a holistic understanding of the caregiver's view and desired outcomes, along with the care recipient's perspective, enables limited resources to be targeted appropriately and interventions to be improved. Even when little change can be made in service delivery, the very act of recognizing caregivers as separate individuals with their own needs has been shown to have positive impacts.

But caregiver assessment is only a tool, not an end in itself. For assessment to matter, the rationale and philosophy underlying support to caregivers and the status of caregivers within the health system need to be made explicit. Values with regard to the roles and responsibilities of families, friends and neighbors, and the private and public sectors, are central. Are caregivers to be assessed only to control their access to resources, to offer them minimal support so they can carry on despite major hardships and long-term dangers to themselves? Or will assessment give them an opportunity to take stock of their situation and participate in a process that enables them to better balance their own needs with caregiving and other responsibilities?

Caregiver assessment is only a tool,  
not an end in itself.

Are we ready to make the paradigm shift that moves caregivers from the shadows to the forefront of policy, agency and worker attention? Indeed, the actualization of the benefits of caregiver assessment depends greatly on political will.

Since the Older American Act's NFCSP began, new resources have provided caregivers with basic information and support services. Medicaid HCBS waiver programs and state-funded programs also offer some services, mainly respite care. Still, less than half of these programs uniformly assess caregiver needs (Feinberg et al., 2004). Further, many current assessments only determine eligibility and do not examine caregivers' situations and needs. How then are services determined? Research clearly shows that no single intervention works for all, and that caregiver support must be tailored to individual situations. According to Nolan and associates (2005), individualized assessment leads to timely, appropriate services and resources which will impact on caregivers' well-being. Caregivers save the health and long-term care system billions of dollars and they are people with their own unanswered needs. Supporting them is a sound economic and moral investment. Systematic, mandated, routine assessment is the key to ensuring a full return on this investment.

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## References

- Arno, P. (February 24, 2002). Economic Value of Informal Caregiving. Orlando, FL: Annual Meeting of the American Association of Geriatric Psychiatry.
- Audit Commission (2004). *Support for carers of older people*. London: Belmont Press.
- Bass, D. (2001). *Content and Implementation of a Caregiver Assessment*. NFCSP Issue Brief. Washington, DC: U.S. Administration on Aging.
- Baxter, E. (2000). Caregiver assessment: Learn about the caregiver distinct from the person with dementia. *Alzheimer's Care Quarterly*, 1, 62-70.
- Borgermans, L., Nolan, M., & Philp, I. (2001). Carers in Europe. In I. Philp (Ed.), *Family Care of Older People in Europe*. Amsterdam: IOS Press.
- Cannuscio, C., Jones, J., Kawachi, I., Colditz, G., Berkman, L., & Rimme, E. (2002). Reverberation of family illness : A longitudinal assessment of informal caregiver and mental health status in the nurses' health study. *American Journal of Public Health*, 92, 1305-1311.
- Carers UK (2002). *Carers Assessments: Good Practice*. London: Author.
- Dhooper, S. (1991). Caregivers of Alzheimer's disease patients: A review of the literature. *Journal of Gerontological Social Work*, 18, 19-37.
- Ellis, K. (1993). *Squaring the Circle*. York, UK: Joseph Rowntree Foundation.
- Fancey, P. & Keefe, J.M. (1999). *Development of Screening and Assessment Tools for Family Caregivers, Phase I: Report on Review of Non-Validated Tools*. Nova Scotia, Canada: Mount St. Vincent University.
- Feinberg, L. F. (2004). The state of the art of caregiver assessment. *Generations*, 27 (4), 24-32.
- Feinberg, L. F. & Newman, S. (2004). A study of 10 states since passage of the National Family Caregiver Support Program: Policies, perceptions and program development. *The Gerontologist*, 44 (6), 760-769.
- Feinberg, L. F., Newman, S., Gray, L., Kolb, K., & Fox-Grage, W. (2004). *The State of the States: A 50-State Study*. San Francisco: Family Caregiver Alliance.

- Gaugler, J., Kane, R., & Langlois, J. (2000). Assessment of family caregivers of older adults. In R. Kane & R. Kane (Eds). *Assessing Older Persons - Measures, Meaning and Practical Applications*. New York: Oxford University Press.
- Geron, S. (1997). Taking the measure of assessment. *Generations*, 21, 5-9.
- Gitlin, L., Hauck W., Dennis M., & Winter L. (2005). Maintenance of effects of the home environmental skill-building program for family caregivers and individuals with Alzheimer's disease and related disorders. *Journals of Gerontology A - Biological and Medical Sciences*, 60(3), 368-74.
- Guberman, N., Keefe, J., Fancey, P., Nahmiash, & Barylak, L. (2001). *Development of Screening and Assessment Tools for Family Caregivers*. Ottawa: Health Transition Fund of Health Canada.
- Guberman, N. & Maheu, P. (2002) Conceptions of family caregivers: Implications for professional practice. *Canadian Journal of Aging*, 21(1), 25-35.
- Guberman, N., Maheu, P., & Maillé, C. (1991). *Et si l'amour ne suffisait pas?: Femmes, familles et adultes dépendants*. Montréal: Les éditions du Remue-ménage.
- Guberman, N., Maheu, P., & Maillé, C. (1993). *Travail et soins aux proches dépendants*. Montréal: Les Éditions du Remue-ménage.
- Guberman, N., Nicholas, E., Nolan, M., Rembicki, D., Lundh, U., & Keefe, J. (2003). Impacts on practitioners using research-based care assessment tools: Experiences from the United Kingdom, Canada and Sweden with insights from Australia. *Health & Social Care in the Community*, 11(4), 345-355.
- Hepworth, David (2003). *Assessment and Support for South Asian Carers*. York, UK: SPRU, University of York.
- Hoskins S., Coleman M., & McNeely D. (2005). Stress in carers of individuals with dementia and community mental health teams: An uncontrolled evaluation study. *Journal of Advanced Nursing*, 50(3), 325-33.
- Kaye, L., Turner, W., Butler, S., Downey, R., & Cotton, A. (2003). Early intervention screening for family caregivers of older relatives in primary care practices. *Family Community Health*, 26(4), 319-328.
- Keefe, J. & Fancey, P. (1997). Financial compensation or home care services: Examining differences among program recipients. *Canadian Journal of Aging*, 9(3), 3-25.
- Kiecolt-Glaser, J. & Glaser, R. (2003). Chronic stress and age-related increases in the proinflammatory cytokine IL-6. *Proceedings of the National Academy of Sciences*, 100(15), 9090-9095.
- Kramer, B.J. (1997). Gain in the caregiving experience: Where are we? What next? *The Gerontologist*, 37(2), 218-232.
- Lee, S., Colditz, G., Berkman, L., & Kawachi, I. (2003). Caregiving and risk of coronary heart disease in U.S. women: A prospective study. *American Journal of Preventive Medicine*, 24, 113-119.

- Levine, C., Reinhard, S., Feinberg, L.F., Albert, S., & Hart, A. (2004). Family caregivers on the job: Moving beyond ADLs and IADLs. *Generations*, 27 (4), 17-23.
- Lundh, U. & Nolan, M. (2003). 'I wasn't aware of that': Creating dialogue between family and professional carers. In M. Nolan, U. Lundh, G. Grant & J. Keady (Eds.), *Partnerships in Family Care*. Buckingham, UK: Open University Press.
- Maddock, A., Kilner, D., & Isam, C. (1998). *Carer Needs Assessment Trial*. Adelaide: Royal District Nursing Service of South Australia.
- Mittelman M., Roth D., Coon D., & Haley W. (2004). Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with Alzheimer's disease. *American Journal of Psychiatry*, 161 (5), 850-856.
- Neal, M., Chapman, N., Ingersoll-Dayton, B., & Emlen, A. (1993). *Balancing work and caregiving for children, adults, and elders*. Newbury Park, CA: Sage Publications.
- New Zealand Guidelines Group (2003). *Assessment Processes for People Aged 65 Years and Over*. Wellington, NZ: Author.
- Nicholas, E. (2003). An outcomes focus in carer assessment and review: Value and challenge. *British Journal of Social Work*, 33, 31-47.
- Nolan, M., Brown, J., & McKee, K. (2005). *Carer's assessment : Lessons from the UK*, Paper presented at the 18th World Congress of Gerontology, Rio de Janeiro, June, 2005.
- Pickard, L. (2004). *The Effectiveness and Cost-Effectiveness of Support and Services for Informal Carers of Older People*. London: Audit Commission.
- Qureshi, H. (2000). Outcomes and assessment with older people. *Research Works*. York, UK: Social Policy Research Unit, University of York.
- Qureshi, H., Arksey, H., & Nicholas, E. (2003). Carers and assessment. In K. Stalker (Ed.). *Reconceptualising Work with 'Carers'*. London: Jessica Kingsley Publishers.
- Ramsdell, J., Jackson, J., Guy, H., & Renvall, M. (2004). Comparison of clinic-based home assessment to a home visit in demented elderly patients. *Alzheimer Disassociation Disorder*, 18 (3), 145-53.
- Richards, S. (2000). Bridging the divide: Elders and the assessment process. *Journal of the British Association of Social Workers*, 30 (1), 37-49.
- Robinson, C. & Williams, V. (2003). Carers of people with learning disabilities and their experience of the 1995 Carers Act. *British Journal of Social Work*, 32, 169-183.
- Scharlach, A., Sobel, E., & Roberts, R. (1991). Employment and caregiver strain: An integrative model. *The Gerontologist*, 31(6), 778-787.
- Schulz, R., O'Brien, A., Bookwala, J., & Fleissner, K. (1995) Psychiatric and physical morbidity of Alzheimer's disease caregiving: Prevalence, correlates and causes. *The Gerontologist*, 35, 771-791.
- Schulz, R. & Beach, S. (1999). Caregiving as a risk factor for mortality. *Journal of the American Medical Association*, 282 (23), 2215-2219.

- Seddon, D. & Robinson, C. (2001). Carers of older people with dementia: Assessment and the Carers Act. *Health and Social Care in the Community*, 9 (3), 151-158.
- Stanley, N. (1999). User-practitioner transactions in the new culture of community care. *Journal of the British Association of Social Workers*, 29 (3), 417-435.
- Stone, R. (2000). *Long-term care for the elderly with disabilities: Current policy, emerging trends, and implications for the twenty-first century*. New York: Milbank Memorial Fund.
- Thompson, L. (2004). *Long-term Care: Support for Family Caregivers (Issue Brief)*. Washington, DC: Georgetown University, Long-Term Care Financing Project.
- Twigg, J. (1993). Integrating carers into the service system: Six strategic responses. *Ageing & Society*, 13, 141-170.
- Twigg, J. (1988). Models of carers: How do social care agencies conceptualise their relationship with informal carers? *International Social Policy*, 18 (1), 53-66.
- Twigg, J. & Atkin, K. (1994). *Carers Perceived: Policy and Practice in Informal Care*. Buckingham, UK: Open University Press.
- U.S. Social Security Administration (2002). *Women and Social Security (Fact Sheet)*. Washington, DC: Author.
- Victorian Order of Nurses (2004). *Caregiver Best Practices Guideline for Community Health providers*. Ottawa: Victorian Order of Nurses.
- Wakabayashi, C. & Donato, K. (2004). *The Consequences of Caregiving for Economic Well-being in Women's Later Life*. Houston, TX: Rice University, Department of Sociology.
- Yee, J. & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *The Gerontologist*, 40 (12) 147-164.
- Zarit, S. & Edwards, A. (1996). Family caregiving: Research and clinical intervention. In R. Woods (Ed.), *Handbook of the Clinical Psychology of Aging*. Chichester, UK: John Wiley & Sons.

## Informant Interviews

Carrie Dennis, Program Coordinator, Home and Community-Based Services, Utah, April 8, 2005.

Cindi Furman, Caregiver Support Manager, Division of Senior Services, Gloucester County, New Jersey, March 30, 2005.

Rhonda Montgomery, Professor, Applied Gerontology, Helen Bader School of Social Welfare, University of Wisconsin, April 1, 2005.

Mike Nolan, Professor of Gerontological Nursing, University of Sheffield, March 24, 2005.

Lorie Van Tilburg, Executive Director, Southern Caregiver Resource Center, San Diego, March 18, 2005

Sonnie Yudell, Program Manager, Utah Caregiver Support Program, March 31, 2005.

## Appendix 1 - Case Study: Mrs. K

Mrs. K, age 71, cares for her 82-year-old husband. A stroke left him with limited mobility on the right side, making walking and transfers difficult. He is cared for at home with some limited Medicaid home care support. Mrs. K feels she must care for her husband to the end, at home, but she was experiencing sleeplessness, abdominal problems, irregular heartbeats and general anxiety. She shared her anxiety and ailments with the home care worker, who spoke to the agency social worker. The social worker proposed a home assessment visit to better understand the sources of her distress and better support her.

In the assessment, Mrs. K revealed that her husband was extremely fearful of falling and constantly asked Mrs. K to fetch things or help him from one place to another. Mrs. K ran up and down the stairs many times a day. Physically exhausted, she had shoulder and back pains. Mr. K, often depressed by his physical losses, required constant moral support. Mrs. K had stopped volunteering, given up many social activities and had little time to enjoy her grandchildren who used to visit regularly. Mrs. K had not seen her doctor recently because she couldn't find time; thus no one has looked into her physical problems. She felt overwhelmed by loss and powerlessness, often teary and listless, but tried to hide this from her husband. At times, she was so overwhelmed and exhausted she went to the basement and turned on the radio so as not to hear her husband. Once, when he couldn't get her attention, he tried going to the bathroom by himself, fell, dirtied himself and remained like this for half an hour. Her guilt led to her incapacity to set limits with him. Her two sons provided some support but she did not feel she could share her emotional state with them. Mrs. K's growing inability to meet her husband's needs and demands put herself and her husband at risk.

Mrs. K was referred for short-term counseling (five sessions), where she discussed her feelings of guilt and total responsibility for Mr. K and received validation to take care of herself. Encouraged, she enlisted the social worker to help her negotiate with her husband around his constant demands and his need to have her continually at his side so that she could get time to take care of her physical health and renew herself with some social activities. She also learned about adult day centers. Mrs. K saw her doctor, who now follows her physical and emotional condition. A physiotherapist trained her to help her husband during transfers without injuring herself.

Four months after the assessment, Mrs. K feels more positive. Mr. K goes to a day center twice a week, freeing up time for her and putting him in contact with professionals and peers who are helping him reframe his own situation, reinforce his autonomy and change his outlook. Mrs. K has arranged for two of the couple's grandchildren to visit their grandfather once a month each for an hour after which they join the couple for supper. Mrs. K has resumed playing cards once a week with her friends while one of her sons visits with Mr. K.

Mrs. K's assessment may have avoided a crisis situation whereby she would have become a client herself, and her husband would have been placed in a nursing home.

# Assessment of Family Caregivers: A Public Policy Perspective

Katie Maslow, MSW, Carol Levine, MA, and Susan Reinhard, PhD, RN

## Abstract

Increasing the use of family caregiver assessment could serve various public policy goals. This paper discusses those goals and describes the current use of family caregiver assessment in publicly funded programs that pay for home and community-based services. It proposes policy options for increasing and supporting the use of family caregiver assessment in those programs and in hospital and nursing home discharge planning for frail older people and adults with disabilities. The paper is intended to assist in evaluating and prioritizing policy options, and it proposes criteria for this purpose. It also identifies important questions about assessment instruments and procedures that are important in thinking about the likely effects of various public policy changes.

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## Introduction

At first glance, public policy and family caregiving seem unlikely co-dependents. Family caregiving exists in the quintessentially private realm of intimate and longstanding relationships and personal obligations based on love, duty, cultural and religious values. Public policy, on the other hand, is the framework for marshaling and allocating resources and establishing the rules and regulations that govern rights and responsibilities in the civic realm.

Family caregiving exists in the quintessentially private realm of intimate and longstanding relationships and personal obligations based on love, duty, cultural and religious values.

But long-term care for people in the U.S. who are ill, disabled or elderly brings the two together. In this arena, public policy depends on unpaid family caregivers.<sup>3</sup> Their work is essentially

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<sup>3</sup> In this paper, the terms “family”, “families” and “family caregivers” are defined broadly and include relatives, partners, friends, or neighbors who have a significant relationship with, and provide a broad range of assistance for, an older person or an adult with a chronic illness or a disabling condition. These individuals may be primary or secondary caregivers; those who provide either part-time or full-time help; and those who live with the care recipient or live separately.

irreplaceable, both because of their longstanding, often deeply personal, bonds with the person who needs care and because providing an alternate source of care is costly and difficult. Without family caregivers, long-term care could not be sustained. And for their part, family caregivers depend on public policy, directly and in less obvious ways. In this relationship, the question might be phrased: Who depends on whom?

Family caregiver assessment is part of the public-policy and family-caregiving relationship. Caregivers directly benefit from caregiver assessments, which generally make them feel recognized as individuals, not just adjuncts to their ill or elderly family member. Caregiver assessments that determine eligibility or appropriateness for a service offer indirect benefits to the caregiver, opening up opportunities for assistance of various kinds; however, they also may foreclose entrance to these services.

Without family caregivers, long-term care could not be sustained.

## Purpose of Paper

This paper discusses the various public policy goals that could be served by increased use of family caregiver assessment. It provides background on the growth in awareness of family caregiving and attention to family caregiver assessment in the U.S.; describes the current use of family caregiver assessment in publicly funded programs that pay for home and community-based services (HCBS); and identifies possible policy options for increasing and supporting the use of family caregiver assessment.

The paper is intended to assist in evaluating and prioritizing policy options and proposes criteria for this purpose. Rather than recommend particular options, it presents an array of possibilities for consideration. In some instances, the same option is proposed for different programs because implementing the same general option raises distinct challenges in different programs. For example, adding family caregiver assessment to the Older Americans Act's National Family Caregiver Support Program is very different from adding it to Medicaid. Different laws, legislative histories, committee processes and vocal stakeholders (for and against change) are involved—to name a few.

## Background: Growth in Awareness of Family Caregiving and Caregiver Assessment

**Family Caregiving.** For most of American history, family caregiving was entirely a family or small-community responsibility. Only people who had no family or who were homeless and destitute came to the attention of city fathers (there were few city mothers in those days). Public health authorities in the late 19<sup>th</sup> and early 20<sup>th</sup> century began to provide home nursing care to poor people, mainly immigrants, and to educate their families in an attempt to stem infectious disease and the presumed evils of urban life.

The Kerr-Mills Act of 1960 provided federal funds to states to pay for medical care for indigent aged citizens, but the current era began in 1965 with the passage of Medicare and Medicaid. Since then, the federal and state governments have been directly involved in paying for medical care and some HCBS for elderly and poor people. Public policymakers asked and continue to ask: “If we provide services for people with extensive care needs, will families abandon their relatives? Why should we pay for what families have always done for free?” In the 1980s and 1990s, looking at “informal caregiving” (the services provided, not the caregivers themselves) became part of the policy world.

A major shift has occurred over the past decade. Federal and state policymakers increasingly see the importance and value of family caregiving. An aging population, dramatic advances in medical treatment, women’s entry into the labor force

and, especially, concern about the spiraling costs of health care fuel this interest. The mantra, “The Baby Boomers are coming, the Baby Boomers are coming!” has not been lost on policymakers.

Caregivers are relative newcomers to

the policy world, pushed forward by a few leaders from their own ranks and advocates from disability, aging and disease-specific organizations. Policymakers, sometimes because of their own family caregiving experiences, have begun to recognize that caregivers are providing an enormous service, not just to their family members but also to the commonweal through their unpaid provision of the major share of long-term care.

A major shift has occurred over the past decade. Federal and state policymakers increasingly see the importance and value of family caregiving. An aging population, dramatic advances in medical treatment, women’s entry into the labor force and, especially, concern about the spiraling costs of health care fuel this interest. The mantra, “The Baby Boomers are coming, the Baby Boomers are coming!” has not been lost on policymakers.

In the 1990s many federal and state government programs supported family caregivers indirectly, by paying for services for the care recipient; some supported family caregivers directly, through services such as respite care and caregiver training (Coleman, 2000; Feinberg & Pilisuk, 1999; Kassner & Williams, 1997). In 2000, landmark federal legislation created the National Family Caregiver Support Program (NFCSP) as part of the Older Americans Act Amendments of 2000 (Public Law 106-501). The NFCSP is the first federal government program to recognize family caregivers explicitly and provide federal funding for services to support them. Since 2000, publicly funded services intended to support family caregivers directly have increased, partly due to NFCSP funding and related federal and state government activities (Feinberg, Newman & Van Steenberg, 2002; Feinberg, Newman, Gray, Kolb & Fox-Grage, 2004; USDHHS, 2003).

Despite greater awareness among policymakers and the increase in publicly funded services for family caregivers, this congruence of interests should not be taken too far. As Feder and Levine (2004) note:

A fundamental assumption underlying health care policy...is that the legal beneficiary is an individual, not a family.... Policymakers tend to view programs as they affect the full population they are intended to serve, rather than programs' impacts on particular individuals. Their focus is on the benefits the law provides to program beneficiaries, not on the varied circumstances facing beneficiaries and families (pp. 103-04).

**Caregiver Assessment.** With the beneficiary as the primary, if not sole, focus, most programs allocate services based on an assessment of that person's needs; they do not require an assessment of the family. Caregivers sometimes are referred to as "resources" but are not recognized as individuals with needs separate from those of the care recipient. When assessment of the family caregiver does occur, the focus is on care needed because of the beneficiary's limitations in activities of daily living (ADLs) not on the family member's special relationship with the care recipient or willingness and ability to provide other kinds of needed care and support (Reinhard, 2004).

Policymakers may be reluctant to require family caregiver assessments for various reasons. They may want to avoid "onerous" record keeping and reporting tasks for program staff. They may also fear that such assessment will bring people "out of the woodwork," creating a new category of clients with expectations for new kinds of services and resulting in complaints rather than satisfaction, when programs cannot meet these expectations without additional funds. Family caregiver advocates have stressed the huge number of family caregivers, bringing attention to

Caregivers sometimes are referred to as "resources" but are not recognized as individuals with needs separate from those of the care recipient.

the issue but also fueling policymakers' concerns that attending to even the most modest of caregiver needs will overwhelm already fragile service systems.

Advocates argue that family caregiver assessment is essential. A 1998 consensus development conference on caregiving sponsored by the National Health Council supported a recommendation to: "Develop a method for assessing the needs of caregivers and providing support for those services and resources they cannot provide on their own" (National Health Council, 1998). In 2003, a group of family caregiver advocates proposed eight "Principles for Change," including the following:

*Principle 8:* Family caregivers must have access to regular comprehensive assessments of their caregiving situation to determine what assistance they may require.

- ◆ Social service and health care providers cannot assume that family members can always provide care for a frail elder or person with disabilities.
- ◆ Family caregivers should be considered an integral part of the long-term care system, as individuals with rights to their own support and assessments of their own needs.
- ◆ An assessment of the family caregiver's strengths, need and preferences constitutes the foundation for developing appropriate and quality long-term care.
- ◆ The availability of family members and others to provide uncompensated care should not be considered in allocating long-term care benefits (as in the Medicaid program) (Family Caregiver Public Policy Coalition, 2003).

In 2004, several policy analysts recommended that family caregiver assessment be required in Medicare and Medicaid-funded home care programs and included in Joint Commission on Accreditation of Healthcare Organizations (JCAHO) standards for hospital discharge planning (Gould, 2004; Riggs, 2004; Vladeck, 2004). Further, the White House Mini-Conference on the Future of Caregiving in June 2005 recommended the "development of a national assessment program for all family and informal caregivers that can assess their need for support services and which can be integrated into the development of care plans" (Mini-Conference, 2005).

In sum, family caregiver assessment is now clearly on the public policy agenda. On the other hand, legislative proposals currently pending in Congress that might be vehicles for increasing family caregiver assessment, for example the Geriatric and Chronic Care Management Act (S. 40 and H.R. 467) and the Lifespan Respite Care Act (S. 1283) do not require it.

## Public Policy Goals and Caregiver Assessment

From the perspective of policymakers, at least five main categories of public policy goals could be served by family caregiver assessment: to keep caregivers providing care; to protect recipients from abuse and neglect; to evaluate caregiving services; to respond to caregiver demands; and to do good.

**Keeping Caregivers Providing Care.** Public policy depends on an unwritten contract with family caregivers to maintain and even increase their level of involvement in long-term care, so an overriding goal is to prevent caregivers from succumbing, physically and mentally, to the rigors of the job. State budgets are struggling to support formal care services, whether in nursing homes or in the community; without family caregivers, they could not provide even what they now do. There is not enough money or workers. Spending money on caregiver services is a prudent way to prevent the greater expense that the loss or decrease of family care would bring. Not all caregivers will want, or accept, or can be given, all services; caregiver assessments can help to target (or ration) services.

At least five main categories of public policy goals could be served by family caregiver assessment: to keep caregivers providing care; to protect recipients from abuse and neglect; to evaluate caregiving services; to respond to caregiver demands; and to do good.

Currently the characteristics and needs of the “primary” consumer (the beneficiary or care recipient), such as income, type of disability, and level of functioning generally are used to target services, although funding availability and professional interest may be the deciding factors. Targeting also could be accomplished by focusing on the caregiver’s characteristics and needs. Although these two sets of needs may also intersect neatly, they may be at variance. For example, a care recipient could have relatively modest needs, and the caregiver serious problems.

**Protection from Abuse and Neglect.** Both caregivers and care recipients are vulnerable populations. Most families try hard to provide good care, but some caregivers are overcome by their obligations, their own illnesses and their circumstances. Assessments can help determine which caregivers suffer so much from physical and social isolation, lack of knowledge about disease or medications, poor mental or physical health, or personal or family problems, that they may abuse or neglect the care recipient. Timely interventions can prevent abuse and neglect and respond when necessary with Adult Protective Services or other action. However, these actions also may intrude upon family privacy and autonomy and may confront cultural barriers.

**Evaluation of Caregiving Services.** Public policymakers have an obligation to evaluate the effectiveness of existing programs. Forward-looking officials want to identify the need for and types of new programs to serve caregivers and be sure that caregivers are receiving appropriate services. Program staff is an important information source, but caregivers' evaluations of the services are essential as well. Assessments of caregivers who are not receiving services can surface the reasons and suggest possible program adjustments or innovations. For example, respite services are often underutilized. Caregiver assessments can help identify why—whether it is how the program is structured, caregivers' worries about the quality of substitute care or the program's inadequate supervision and management. These problems can then be addressed more directly (Reinhard, Bemis & Huhtula, 2005).

**Responding to Caregivers' Demands.** Public policy responds to many pressures—political agendas, funding streams, needs assessments and research, for example. Consumer demand is an important impetus to creating public policy, for public policymakers are sensitive to the people who elect them, pay their salaries and challenge them in meetings and the media. Although caregiver demand for services is beginning to increase, caregivers have not yet fully capitalized on their numbers, their importance to the health care and social service sectors, and the power of their stories. Many caregivers, perhaps most, do not identify themselves as caregivers; some even reject that designation. They feel that they should be able to do the job alone, an attitude that professionals, others in their families and communities, and even the care recipient often reinforce. This attitude may change as Baby Boomers, more accustomed to asserting their rights and demanding services, come of (old) age.

**Doing Good.** By and large policymakers want to do good and feel that their public service improves their constituents' lives and their communities. Keenly aware of the competition for resources, they try to balance one group's needs against another's equally urgent claims. Making hard choices is not easy, so the motivation to do good alone will not allow caregiving assessment to rise high on the public policy agenda. One or more other goals also will need to be in place.

## Policy Options for Increasing Family Caregiver Assessment in Public Home and Community-Based Services Programs

**Overview.** The main programs that pay for most publicly funded home and community-based care for frail older people and adults with physical disabilities are Older Americans Act programs, Medicaid, and state-funded programs. These programs help family caregivers by paying for services for the care recipient and increasingly support services explicitly for the caregiver. Yet, many do not require family caregiver assessment. This section describes each of these programs, notes

their reported use of family caregiver assessment, and identifies policy options for increasing the use of such assessment in each program. Many public programs that pay for HCBS now allow payment to some family caregivers<sup>4</sup> and “consumer direction.”<sup>5</sup> Moreover, many states are currently working to rebalance their long-term care systems to redress institutional bias and integrate HCBS funding by various public programs in response to the U.S. Supreme Court decision in the *Olmstead* case.<sup>6</sup> Implications of both these developments for the use of family caregiver assessment are also discussed.

Other considerations in weighing policy options are the level of government at which the decision will be made, whether the policy results in a requirement or simply latitude and whether new funds are provided to implement the policy. A federal program that requires family caregiver assessment likely would have a different impact, for example, than a federal program that allows family caregiver assessment but lets states decide whether to require such assessments. Similarly, an option that allows the use of *existing program funds* for family caregiver assessment differs from one that would provide *new funds* for such an assessment.

Other considerations spring from how the assessment would be conducted. Box 1 (page 66) outlines questions to ask about the assessment instrument and procedures that would be used in connection with any of the proposed policy options. Answers to these questions may influence attitudes about the desirability of particular options.

**Older Americans Act Programs.** The Older Americans Act (OAA) was enacted in 1965, and most recently reauthorized in 2000. At the federal level, the Administration on Aging (AoA) administers OAA programs; at the state level, State Units on Aging (SUAs); and at the regional, county and local levels, the Area Agencies on Aging (AAAs). AoA could pay for or otherwise support family caregiver assessment through the NFCSP, other OAA-funded HCBS and/or research, evaluation and technical assistance programs.

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<sup>4</sup> Federal payment for spouses and parents of dependent children requires special waivers.

<sup>5</sup> “Consumer direction” is a broad term and includes the potential for consumers to select and supervise the people who will provide personal care.

<sup>6</sup> The 1999 Supreme Court decision in *Olmstead v. L.C.* (119 S.C. 2176 (1999)) affirmed the right under the Americans with Disabilities Act of qualified individuals to be transferred from institutions to their communities with appropriate services.

**Box 1. What to Ask About Family Caregiver Assessment:  
Who, What, When, Why, and How Often**

- ◆ Who would be assessed? Would it be only the primary family caregiver? Who would have authority to identify the family caregiver(s) to be assessed?
- ◆ Who would conduct the assessment?
- ◆ What assessment instrument would be used? Who would have authority to select or design it?
- ◆ How would the privacy rights of the care recipient under HIPAA be balanced with the caregiver's need to have full information about the level of care required? Do program staff need explicit authorization from the client to contact family caregivers about the client's care?
- ◆ Would the assessment results be used to determine eligibility for program services? If so, would the results determine only the family caregiver's eligibility for family support services, or would the results also affect the care recipient's eligibility for services?
- ◆ What would happen if the family caregiver(s) refused to be assessed? How would such refusal affect the care recipient's eligibility for program services?
- ◆ What would happen if the family caregiver assessment identified needs that could not be met through services provided or paid for by the program? What entitlement would the caregiver have to such services, and conversely, what obligation would government have to provide or pay for the services?
- ◆ How often would reassessment be required?
- ◆ How would the implementation and quality of the assessment and reassessment procedures be monitored and assured?

*The National Family Caregiver Support Program (NFCSP).* The NFCSP requires all SUAs and AAAs to offer, at a minimum, the following services to benefit family caregivers:

- ◆ information about available services;
- ◆ assistance in gaining access to supportive services;
- ◆ individual counseling, organization of support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their roles;

- ◆ respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities; and
- ◆ supplemental services on a limited basis, to complement the care provided by caregivers.

The NFCSP serves family caregivers of adults age 60 and older, with priority for older adults with the greatest social or economic need. Designated percentages of NFCSP funds are reserved for grandparents aged 60 and over caring for grandchildren and for Native American caregivers. In federal fiscal year 2002, the NFCSP provided information about available services to over 4 million people, assistance in gaining access to services to 440,000 people, counseling and training to 182,000 people, respite care to 76,000 people, and supplemental services to 56,000 people (AoA, 2004).

A 50-state survey of family caregiver support programs conducted by the National Center on Caregiving at Family Caregiver Alliance (Feinberg et al., 2004) provides a valuable baseline in thinking about state practices in family caregiver assessment. In response to the 50-state survey, almost all states reported that they do assess family caregivers in the state’s NFCSP-funded program. However, what caregiver assessment means varies across states. Some respondents believed that simply asking care recipients about family caregivers constitutes “caregiver assessment.” Of the states that reported that they assess family caregivers in their NFCSP-funded program, slightly less than half used a uniform assessment instrument that includes questions about the family caregiver’s needs and situation.<sup>7</sup> Three states (Iowa, Louisiana, New Hampshire) said they assess only the care recipient in their NFCSP-funded program, but one of them (Louisiana) uses a uniform assessment instrument that includes the family caregiver’s needs and situation, even though the caregiver is not assessed directly.

What caregiver assessment means varies across states.

Among states that use a uniform instrument with questions about the family caregiver’s needs and situation, the six most frequently reported areas of assessment were: (1) ability to provide care; (2) basic caregiver demographics; (3) caregiver strain; (4) care frequency; (5) caregiver physical health; and (6) caregiver depression.

Four *policy options* for the NFCSP to increase the use of caregiver assessment are:

- ◆ A congressional amendment could add family caregiver assessment to the types of services states must offer and allow them to use NFCSP funds for this service.

<sup>7</sup> In the context of the 50-state survey, the term “situation” was intended to mean the status and circumstances of the caregiver from his/her own perspective, e.g., the caregiver’s physical and mental health and behavioral symptoms of the person being cared for that upset the family caregiver and cause strain.

- ◆ A congressional amendment could add family caregiver assessment as an optional service that states can choose to provide with NFCSP funds. If such an amendment passed, states could choose whether to require family caregiver assessment for their NFCSP-funded services.
- ◆ AoA could use NFCSP funds to commission a detailed analysis of family caregiver components of the various assessment instruments and procedures that states currently use in their NFCSP. This analysis could be especially useful for state NFCSPs that do not currently use an instrument with a systematic family caregiver component.
- ◆ AoA could use NFCSP funds to fund a pilot study in one or more states to compare program procedures and outcomes when a family caregiver assessment is or is not used.

*Other OAA Programs.* OAA programs other than the NFCSP pay for many services and interventions intended to develop, coordinate and provide appropriate supports for people age 60 and over. Home and community-based services funded by OAA programs include home-delivered meals, transportation, home care (e.g., homemaker and chore services), telephone reassurance, respite and home modifications. In addition, OAA programs pay for research, program analysis and technical assistance to support aging network agencies.

The 50-state survey did not collect information about OAA programs other than the NFCSP. Thus, national data are not available on the use of family caregiver assessment in these other OAA programs.

Two *policy options* that could increase caregiver assessment in other OAA programs are:

- ◆ A congressional amendment could add family caregiver assessment to the types of services states must, or are allowed to, provide with OAA funds. With an amendment that allowed states to provide family caregiver assessments with OAA funds, the states then would have to decide whether to require AAAs and other contracted agencies to provide these assessments and what training is needed to do so.
- ◆ AoA could use OAA research and demonstration program funds to develop, implement and evaluate a family caregiver assessment instrument and procedure for use either generally or in one or more OAA-funded program.

**Medicaid.** The federal Medicaid program, enacted in 1965, requires states to pay for home health services, including nursing, home health aides, medical supplies and medical equipment for certain categories of individuals (including aged and disabled) who meet specified financial, medical and/or functional eligibility criteria (O’Keeffe, Smith, Carpenter, Doty & Kennedy, 2000). The program allows states to

pay for additional services, including personal care and physical therapy. The federal Medicaid program also allows states to apply for waivers to pay for a wider array of HCBS for aged/disabled people who meet financial eligibility criteria and would otherwise require nursing home care reimbursable by Medicaid. These waivers are referred to as 1915(c) or HCBS waivers or 1115 waivers. As of 2000, all states had one or more of these waivers (Wiener, Tilly & Alecxih, 2002).

Medicaid expenditures to keep people in their homes and communities are growing by one to three percent per year (Burwell, Sredl & Eiken, 2005). Federal law requires, however, that Medicaid services, including services paid for under 1915(c) HCBS and 1115 waivers, must address the beneficiary's needs, not the needs of the family unit. In response to the 50-state survey, only ten states (Hawaii, Massachusetts, Minnesota, New Hampshire, New Jersey, New Mexico, North Carolina, Ohio, Pennsylvania and Utah) reported that they assess family caregivers in addition to assessing the person with disability in their Medicaid 1915(c) HCBS waiver program (Feinberg et al., 2004; Feinberg & Newman, 2005).<sup>8</sup> All but one of these states (New Hampshire) also reported using a uniform assessment instrument with questions about the family caregiver's needs and situation. An additional 15 states (Connecticut, Delaware, Florida, Georgia, Kansas, Louisiana, Massachusetts, Maryland, Michigan, Montana, Oklahoma, South Carolina, South Dakota, Virginia and Washington) who reported that they assess only the care recipient use a uniform assessment instrument that includes some questions about the family caregiver's needs and situation, even though the caregiver is not assessed directly. Surprisingly, almost half of the Medicaid 1915(c) HCBS waiver programs did not collect data on family caregivers and could not answer the question: "If the family caregiver is not considered the client in the program, approximately what percentage of your clients have a family caregiver?"

Responses from all states that reported their state's Medicaid 1915(c) HCBS waiver program uses a uniform instrument with questions about the family caregiver's needs and situation show that the six most frequently reported areas of family caregiver assessment were: (1) caregiver willingness to provide care; (2) ability to provide care; (3) care frequency; (4) caregiver strain; (5) care duration; and (6) caregiver physical health. Four of these six match those most frequently reported by NFCSP assessments (ability to provide care, care frequency, caregiver strain, and caregiver physical health).

The 50-state survey did not collect information about regular Medicaid programs. Thus, national data are not available on the use of family caregiver assessment in these programs.

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<sup>8</sup> Respondents for some of these states may have believed that asking care recipients about family caregivers constituted "caregiver assessment."

Four *policy options* to increase caregiver assessment in Medicaid are:

- ◆ A congressional amendment could add family caregiver assessment to the types of services states are required to provide in their regular Medicaid program.
- ◆ A congressional amendment could add family caregiver assessment as an optional service states can choose to provide in their regular Medicaid program.
- ◆ The federal Centers for Medicare and Medicaid Services (CMS) could develop a notice for state Medicaid agencies to clarify existing federal policy that Medicaid funds can be used for family caregiver assessment (as part of the full “participant” assessment) in regular Medicaid and Medicaid waiver programs.
- ◆ CMS, AoA, the Office of the Assistant Secretary for Planning and Evaluation (ASPE) or another federal agency could commission a detailed comparison of the family caregiver components in the uniform assessment instruments currently being used by states in their Medicaid waiver programs, with states that do not have these components.

**State-Only Programs.** Many states use state general funds or other state-only funds to pay for various HCBS for older people and adults with physical disabilities (Feinberg et al., 2004; Kassner & Williams, 1997; Wiener et al., 2002). In response to the 50-state survey, 20 states reported that family caregivers are assessed in at least one of the HCBS programs funded entirely by the state (Feinberg et al., 2004). In 14 of these 20, programs use a uniform assessment instrument that includes questions about the family caregiver’s needs and situation. Among states using such an instrument, the six most frequently reported areas of family caregiver assessment were the same as those reported in the NFCSP assessments: (1) ability to provide care; (2) caregiver strain; (3) basic caregiver demographics; (4) caregiver physical health; (5) care frequency; and (6) caregiver depression.

One *policy option* to increase caregiver assessment among state-funded programs is:

- ◆ States that do not currently use a family caregiver assessment in their state-funded HCBS program(s) could evaluate the benefits by seeking information from states that do use such an assessment.

**Programs that Allow Payment to Family Caregivers or Consumer Direction.** Many publicly funded HCBS programs allow payment to family members to provide the care in HCBS. Based on the 50-state survey, 44 states and the District of Columbia have at least one HCBS program that allows payment to family members, including 59 percent of state NFCSPs, 40 percent of state-only programs and 74 percent of Medicaid 1915(c) HCBS waiver programs (Feinberg et al., 2004; Feinberg & Newman, 2005).<sup>9</sup>

<sup>9</sup> Medicaid waiver programs do not allow payment to spouses.

Consumer-directed care is also allowed by some publicly funded HCBS; and many programs that allow consumer direction also allow payment for family members to provide care (Doty, 2004; Feinberg et al., 2004; NASUA, 2004; Tilly & Wiener, 2001). Responses to the 50-state survey (Feinberg et al., 2004) show that all but two states (Delaware and New York) had at least one HCBS program that allows consumer direction; this includes 86 percent of state NFCSPs, 62 percent of state-only programs, and 65 percent of Medicaid 1915(c) HCBS programs. A 2001 inventory of public programs that allow consumer direction found that 80 percent also allowed payment to family members to provide care (Doty & Flanagan, 2002).

When a family member is being paid to provide care or when a care recipient is not able or does not want to make decisions about services (e.g., decisions about hiring and directing the provider) and a family member takes over this task, family caregiver assessment might be particularly important—prudent, in fact, if both situations occur. On the other hand, the intent of paying family members and allowing consumer direction is to increase choice and control for the care recipient and family, and to avoid bureaucratic rules and intrusive professional monitoring (Doty, 2004; Feinberg & Newman, 2004).

When a family member is being paid to provide care or when a care recipient is not able or does not want to make decisions about services (e.g., decisions about hiring and directing the provider) and a family member takes over this task, family caregiver assessment might be particularly important—prudent, in fact, if both situations occur.

A *policy option* for programs that allow payment to family caregivers and consumer direction is:

- ◆ AoA could commission an analysis of the pros and cons of family caregiver assessment in public programs that pay for HCBS and allow either payment of family members or consumer direction or both. This analysis could: include a review of family caregiver assessment instruments and procedures, if any, in existing programs, including Cash and Counseling and Independence Plus waiver programs;<sup>10</sup> identify items for a possible assessment instrument, including items that address the family member's ability to make decisions about care and his/her ability to provide care; and evaluate the implications for a government agency of using an assessment instrument that would identify potential problems with the safety and quality of care provided for the person and the care decisions made for him/her by a family member.

<sup>10</sup> Neither of these programs currently requires family caregiver assessment.

**State Service-Integration Initiatives.** Over the past 20 years, a few states have achieved some success in integrating HCBS funded by various programs (Coleman, 1998; Dize & Link, 2003; Justice, 1987). Integration of services is now a high priority for many states, in part because fragmentation of HCBS limits the access to care in the community that the *Olmstead* decision requires (Feinberg et al., 2004; Wiener et al., 2002).

Since the *Olmstead* decision, the federal government has required states to develop plans to increase access to home and community care and rebalance their long-term care services by reducing the existing bias toward institutional care. The federal New Freedom Initiative, created by executive order in 2001, provides grants to help states with this function:

- ◆ Real Choice Systems Change grants to support states' development of HCBS; from 2001 to 2005, 238 grants, totaling \$188 million, were awarded to 50 states and U.S. territories; and
- ◆ Aging and Disability Resource Centers grants to support the development of various procedures to help consumers learn about and access services at the community level; in 2003 and 2004, 24 such grants, totaling \$19 million, were awarded to 23 states and one territory, and about 20 more grants will be awarded in 2005.

The *Olmstead* decision and related federal and state government activities create opportunities for increasing the use of family caregiver assessment. Caregiver assessments could support decisions to place or maintain a disabled individual in the community and reveal areas where support beyond family care is required.

In the 50-state survey, only five states reported using a uniform family caregiver assessment in all their programs that provide HCBS (Feinberg et al., 2004). Two of these state assessment forms, from Minnesota and Washington, are shown in Appendix 1 on page 81. The Washington form is currently being revised, but at present, care managers in the state are required to use this form. In Minnesota, care managers are not required to use the family caregiver assessment, and the proportion of care managers who do use it is not known. Fifteen states reported that they have single entry points for accessing at least some HCBS; 11 of these states provide access to family caregiver services in their single entry point systems (Feinberg et al., 2004), but it is not clear how many offer family caregiver assessment in these settings.

Six *policy options* to further use of caregiver assessment in state service-integration efforts are:

- ◆ Each state could implement a uniform family caregiver assessment in its service-integration efforts—as part of or separate from the care recipient assessment.

- ◆ States could use a uniform family caregiver assessment in all single entry point settings—as part of or separate from the care recipient assessment.
- ◆ Through “terms and conditions,” CMS could require states to implement a uniform family caregiver assessment as part of initiatives funded with new Real Choice Systems Change grants. Alternatively, CMS and AoA could allow and encourage states to implement such an assessment as part of grant-funded initiatives.
- ◆ Through “terms and conditions,” CMS and AoA could require—or allow and encourage—states to implement a family caregiver assessment in new Aging and Disability Resources Centers established with federal grants.
- ◆ CMS and/or AoA could commission a study to evaluate the pros and cons of providing family caregiver assessments in caregiver resource centers or a state’s general single entry points for HCBS.
- ◆ CMS and/or AoA and other federal government agencies could fund a multi-state demonstration project to implement and evaluate the use of a uniform family caregiver assessment in HCBS; outcomes to be measured in the demonstration could include the quality of care provided for the recipient and physical and emotional health of the family caregiver.

## Policy Options for Increasing Family Caregiver Assessment in Transitions to Home and Community-based Care

This paper has focused thus far on publicly funded HCBS, but many older people and adults with disabilities do not use these services. Their primary connection with public policy is through Medicare, and indirectly through private insurance. When these people are discharged from acute care hospitals or subacute, rehabilitation or Medicare-funded skilled nursing facilities, their families often assume or re-assume responsibility for “doing whatever needs to be done.” That includes helping with ADLs, managing finances, supervising paid service providers and managing extremely complex medication schedules and high-tech medical equipment (Levine & Hart, 2004). Discharge planning procedures typically do not include a family caregiver assessment to help determine whether the family is able and willing to provide this care and what kind of assistance is needed to assure a “safe and adequate” transition (to use Medicare terminology).

Public policy mechanisms for increasing the use of family caregiver assessment in discharge planning include the regulations and standards of public payers, e.g., Medicare, Medicaid and the Department of Veterans Affairs (VA); accreditation organizations with deemed status for particular facilities (e.g., the Joint Commission

for Accreditation of Healthcare Organizations [JCAHO]); and public agencies that regulate private insurance.

Monitoring, quality assurance procedures and training would need to back up such regulations and standards. Facility staff would need to know how to conduct the assessments and incorporate assessment findings into discharge planning.

Only a small proportion of people discharged to the community after short-term stays in hospitals, nursing homes, or rehabilitation facilities are likely to qualify for HCBS. Protocols would have to be developed to identify the discharges for which a family caregiver assessment is required, such as cases where long-term chronic care is anticipated or where care may not be long-term but intensive nonetheless, such as following cardiac or joint replacement surgery.

A much larger proportion of residents discharged to the community after long-term stays in nursing home and other residential care facilities are likely to need HCBS. Requiring a family caregiver assessment for every such discharge might be appropriate.

Nursing homes currently use a standardized assessment instrument, the Minimum Data Set (MDS), to record information about residents at admission, throughout their stay and on discharge. The existing MDS form for discharge assessments only asks whether the resident is being discharged to home with or without home health services, to a board and care or assisted living facility, or to an acute care, psychiatric or rehabilitation hospital or a facility for people with mental retardation or developmental disabilities. Medicare, Medicaid and the VA, which together pay for most nursing home care, could require a family caregiver assessment at discharge. Such a requirement would seem to fit well with *Olmstead*-related objectives for facilitating access to appropriate community care for people with disabilities.

Most assisted living facilities do not use a standardized assessment instrument, and most residents in these facilities pay privately for their care. However, many states are creating regulations for assisted living facilities and could require family caregiver assessment should a resident leave the facility to go home.

Discharges from home health care can be as problematic for families as discharges from health and residential care facilities. In a study of caregivers of stroke and brain injury patients, Albert and colleagues (in preparation) found that many did not even realize until a few days before the case was closed that home care services were going to end. Many were not prepared to take over the care on their own and they were not given referrals to any caregiver services.

Home health agencies that provide Medicare- and Medicaid-funded care use a standardized assessment instrument, Outcome and Assessment Information Set for Home Health Care (OASIS). This instrument asks whether the person lives alone or with a spouse, significant other, other family member or friend; who helps the person;

how often, and with what activities. The instrument includes a section on caregiver management of oxygen, IV/infusion equipment, enteral/parenteral nutrition, ventilator therapy equipment or supplies and asks about the caregiver's ability to use the equipment (set up, monitor, and change equipment reliably and safely, add fluids or medication, clean/store and dispose of equipment or supplies using proper technique). These questions pertain to the caregiver's ability, not compliance or willingness. Additional OASIS items for discharges ask whether the patient receives health, personal or support services or assistance from family, friends or other community agencies.

Before deciding to require a family caregiver assessment as part of discharge planning for hospitals, subacute and rehabilitation facilities, nursing homes, other health care facilities and home health agencies, questions about the assessment instrument and procedures would have to be addressed (see Box 1 on page 66). In addition, difficult questions would have to be answered about the facility's and payer's responsibility and liability with respect to transitional needs identified in the assessment. In current practice, health care and home health agency responsibilities and related liability are generally perceived to end with the discharge. No clear chain of responsibility exists to manage the transition, to see that information has been transferred appropriately and to assure that identified needs for care, including family caregiver assessments, have been put in place. In connection with the New Freedom Initiative, CMS recently has allowed funding for rent deposits and other transitional housing needs for people discharged from long-term care facilities. An important next step would be policy direction about other transitional needs, including needs identified in a family caregiver assessment.

The VA Office of Care Coordination currently plans to use a family caregiver assessment to identify high-risk caregivers of veterans in its Care Coordination Home Telehealth (CCHT) program. Long-range plans include: 1) incorporation of the Zarit Burden Inventory and Caregiver Strain Index into an electronic messaging format to be used by family caregivers; 2) encouragement of family caregivers to use the instruments periodically to monitor change; 3) development of procedures to correlate caregiver scores and patient outcomes; and 4) use of caregiver assessment as a quality indicator and condition of participation for all VA health care networks (Campbell, personal communication, June 30, 2005). In implementing these plans, the Office of Care Coordination will probably have to address questions about VA responsibility and liability for meeting family caregiver needs identified with the assessment instruments.

In current practice, health care and home health agency responsibilities and related liability are generally perceived to end with the discharge. No clear chain of responsibility exists to manage the transition, to see that information has been transferred appropriately and to assure that identified needs for care, including family caregiver assessments, have been put in place.

## Other Public Policies to Consider

Many other policies could support family caregiver assessment. For example, government could fund:

- ◆ Psychological, behavioral and social research on caregiving that would support the development of the assessment instrument or instruments.
- ◆ Analysis of use of family caregiver assessment in other countries' HCBS programs.
- ◆ Training for health care and social service professionals and consumer advocacy groups about the value and administration of caregiver assessment.
- ◆ Development of quality indicators to monitor the use and outcomes of family caregiver assessment, especially for transitional care.
- ◆ Inclusion of family caregiver assessment in the Medicare chronic care, case management and pay-for-performance demonstration projects mandated by the Medicare Modernization Act.
- ◆ Training about the implications of the Health Information Accessibility and Accountability Act (HIPAA) for staff communication with family caregivers, including the patient information that can be given to family caregivers while still protecting the patient's privacy.
- ◆ Analysis of the implications of incorporating the results of family caregiver assessments in electronic medical records.

For any public policy option to be chosen, it should be practical, acceptable, affordable and ethical.

For any public policy option to be chosen, it should be practical, acceptable, affordable and ethical. Box 2 presents questions to use in applying these criteria to family caregiver assessment.

**Box 2. Criteria for Evaluating Public Policy Options**

- ◆ **Practical:** Where are the points at which other agendas and caregiver assessment coincide and where there is some likelihood of success? Where is there synergy?
- ◆ **Acceptable:** Would caregivers find it useful or intrusive? How will caregivers learn about it and begin to demand it? Would professionals implement it? Would policymakers feel it meets their goals? Would consumer advocates support it?
- ◆ **Affordable:** Can it be built into existing programs with minimal extra cost? Is there additional funding available or could it become available? What policies are the most cost-effective? And how would cost-effectiveness be measured? What are the costs of not doing it?
- ◆ **Ethical:** Does the policy balance the need to serve the most vulnerable caregivers with the importance of preventing vulnerability in other individuals?

## Conclusion

This paper has outlined many public policy options to increase and support the use of family caregiver assessments; proposed criteria for use in evaluating these and any additional policy options that may emerge; and raised questions about assessment procedures and instruments that are important in thinking about the likely effects of various public policy changes. The authors hope that the ideas and information presented in the paper will help in prioritizing possible policy options and addressing issues such as mandatory requirements; reporting, reimbursement and information technology; the relationship between assessment findings for the care recipient and the caregiver; and the implications for government agencies and private health care and residential care facilities of identifying family caregiver needs that are outside the scope of services usually provided by these agencies and facilities.

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## References

- Administration on Aging. (2004). *The Older Americans Act: National Family Caregiver Support Program (Title III-E and Title VI-C): Compassion in Action*. Washington, DC: U.S. Department of Health and Human Services, Administration on Aging.
- Albert, S., Hokenstad, A., Halper, D., Hart, A., Gould, D., & Levine, C. (In preparation). *This Case Is Closed: How Family Caregivers Manage the Transition when Formal Home Care Services are Terminated*.
- Burwell, B., Sredl, K., & Eiken, S. (2005). *Medicaid Long Term Care Expenditures in FY 2004*. Cambridge, MA: Medstat.
- Coleman, B. (1998). *New Directions for State Long-Term Care Systems: Second Edition*. Washington, DC: AARP Public Policy Institute.
- Coleman, B. (2000). *Helping the Helpers: State-Supported Services for Family Caregivers*. Washington, DC: AARP Public Policy Institute.
- Dize, V. & Link, G. (2003). *The Role of Coordination in the Family Caregiver Support Program*. Washington, DC: National Association of State Units on Aging.
- Doty, P. (2004). *Consumer-Directed Home Care: Effects on Family Caregivers: Policy Brief*. San Francisco, CA: National Center on Caregiving, Family Caregiver Alliance.
- Doty, P. & Flanagan, S. (2002). *Highlights: Inventory of Consumer-Directed Care Programs*. Washington, DC: U.S. Department of Health and Human Services.
- Family Caregiver Public Policy Coalition (2003). *Family Caregiving and Public Policy: Principles for Change* accessed at: [http://www.caregiver.org/caregiver/jsp/content/pdfs/op\\_2004\\_principles.pdf](http://www.caregiver.org/caregiver/jsp/content/pdfs/op_2004_principles.pdf)
- Feder, J. & Levine, C. (2004). Explaining the paradox of long-term care policy. In C. Levine & T. Murray (Eds.). *The Cultures of Caregiving: Conflict and Common Ground among Families, Health Care Professionals, and Policy Makers*. Baltimore, MD: Johns Hopkins University Press, pp. 103-112.

- Feinberg, L. & Newman, S. (2004). A Study of 10 States Since Passage of the National Family Caregiver Support Program: Policies, Perceptions, and Program Development. *The Gerontologist*, 44 (6), 760-769.
- Feinberg, L. & Newman, S. (2005). *Medicaid and Family Caregiving: Services, Support and Strategies Among Aged/Disabled HCBS Waiver Programs in the U.S.* New Brunswick, NJ: Rutgers Center for State Health Policy.
- Feinberg, L. & Newman, S. (2005). *Consumer Direction and Family Caregiving: Results from a National Survey.* New Brunswick, NJ: Rutgers Center for State Health Policy.
- Feinberg, L., Newman, S., Gray, L., Kolb, K., & Fox-Grage, W. (2004). *The State of the States in Family Caregiver Support: A 50-State Study.* San Francisco, CA: Family Caregiver Alliance.
- Feinberg, L., Newman, S., & Van Steenberg, C. (2002). *Family Caregiver Supports: Policies, Perceptions, and Practices in 10 States Since Passage of the National Family Caregiver Support Program.* San Francisco, CA: Family Caregiver Alliance.
- Feinberg L. & Pilisuk T. (1999). *Survey of Fifteen States' Caregiver Support Programs.* San Francisco, CA: Family Caregiver Alliance.
- Gould, D. (2004). Measuring What Matters: Levers for Change. In C. Levine (Ed.), *Family Caregivers on the Job: Moving Beyond ADLs and IADLs.* New York, NY: United Hospital Fund of New York.
- Justice, D. (1987). Policy coordination and integration: Alternative state approaches: Overview. In *Building Affordable Long-Term Care Alternatives.* Washington, DC: National Governors Association.
- Kassner, E. & Williams, L. (1997). *Taking Care of Their Own: State-Funded Home and Community-Based Care Programs for Older Persons.* Washington, DC: AARP.
- Levine, C. & Hart, A. (2004). Doing whatever needs to be done: Caregivers' perspectives on ADLs and IADLs. In C. Levine (Ed.), *Family Caregivers on the Job: Moving Beyond ADLs and IADLs.* New York, NY: United Hospital Fund of New York.
- Mini-Conference on the Future of Caregiving. (2005). *Final Report and Recommendations Submitted to the 2005 White House Conference on Aging Policy Committee.* Washington, DC: Author.
- National Association of State Units on Aging and National Council on the Aging (2004). *States' Experiences Implementing Consumer-Directed Home and Community Services: Results of the 2004 Survey of State Administrators, Opinion Survey, and Telephone Interviews.* Washington, DC: National Association of State Units on Aging.
- National Association of State Units on Aging (2001). *Systems Development for Family Caregiver Support Services: AoA Caregiver Listserv Summary: Research Brief #1.* Washington, DC: Author.
- National Health Council. (1998). *Consensus Development Conference on Caregiving: Agenda for Action: Discussion Paper.* Washington DC: Author.

- O’Keeffe, J., Smith, G., Carpenter, L., Doty, P., & Kennedy, G. (2000). *Understanding Medicaid Home and Community Services: A Primer*. Washington, DC: U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Disability, Aging, and Long Term Care Policy.
- Reinhard, S. (2004). The work of caregiving: What do ADLs and IADLs tell us? In C. Levine (Ed.), *Family Caregivers on the Job: Moving Beyond ADLs and IADLs*. New York, NY: United Hospital Fund of New York.
- Reinhard, S., Bemis, A., & Huhtala, N. (2005). *Defining Respite Care - Discussion Paper*. New Brunswick, NJ: Rutgers Center for State Health Policy.
- Riggs, J. (2004). A family caregiver policy agenda for the twenty-first century. *Generations*, 27 (4), 68-72.
- Thompson L. (2004). *Long-Term Care: Support for Family Caregivers: Issue Brief*. Washington DC: Georgetown University Long-Term Care Financing Project.
- Tilly, J. & Wiener, J. (2001). Consumer-directed home and community services programs in eight states: Policy issues for older people and government. *Journal of Aging and Social Policy*, 12 (4), 1-26.
- U.S. Department of Health and Human Services, Administration on Aging. (2003). *The Older Americans Act National Family Caregiver Support Program: Compassion in Action: Executive Summary*. Washington, DC: Administration on Aging.
- Vladeck, B. (2004). You can’t get there from here: Dimensions of caregiving and dementias of policymaking. In C. Levine (Ed.), *Family Caregivers on the Job: Moving Beyond ADLs and IADLs*. New York, NY: United Hospital Fund of New York.
- Wiener, J., Tilly, J., & Alexih, L. (2002). Home and community-based services in seven states. *Health Care Financing Review*, 23 (3), 89-114.

## Personal Communication

Campbell, N., Department of Veterans Affairs, Office of Care Coordination, June 30, 2005.

Appendix 1:

Caregiving Components of Two States' Uniform Assessment tools for HCBS

Minnesota's Long Term Care Consultation Services Assessment Form

**P. Caregiver Assessment** R1 R2

*(Introduce yourself to caregiver.)* (NAME OF REFERRAL OR PERSON) told us you were the person most involved in helping with (NAME OF PERSON's) care, so we have a few questions for you.

Relationship to care receiver: \_\_\_\_\_

P1 First, how often do you give care to (NAME OF PERSON)? Would you say you give care:

Every day       Less than once a week       At least once a week  
 Several times a week       Don't know

P2 What kind of help do you give (NAME OF PERSON)? (ASK:) Do you give.

	Yes	Comments
Personal care (such as help with bathing, dressing, using the toilet, getting in and out of the bath, and feeding)	<input type="checkbox"/>	_____
Housekeeping (such as help with meal preparation, cleaning and laundry)	<input type="checkbox"/>	_____
Transportation	<input type="checkbox"/>	_____
Shopping and errands	<input type="checkbox"/>	_____
Supervision for safety	<input type="checkbox"/>	_____
Money management	<input type="checkbox"/>	_____
Other	<input type="checkbox"/>	_____

(SPECIFY) \_\_\_\_\_

P2a How long have you been helping (NAME OF PERSON) with this care? \_\_\_\_\_

P3 In the last two weeks, how many hours did you spend giving care to (NAME OF PERSON)? \_\_\_\_\_ hours in last two weeks

P4 Are you employed full-time, part-time, or are you not employed?

Full-time       Part-time       Not working

P5 If you were unable to continue with care, who would take your place?

Nobody       Other (SPECIFY) \_\_\_\_\_

P6 How is your own health? Would you say it is excellent, good, fair or poor?

Excellent       Good       Fair       Poor       No response

P7 Considering the care you provide for (NAME OF PERSON), I would like to ask you if various aspects of your life have become worse, the same, or better. Let's start with...

	Worse	Same	Better	Don't Know	Comments/ Plan Implications
a. Relationship with (PERSON)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
b. Relationships with other family members	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
c. Relationships with friends	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
d. Your health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
e. (IF APPLICABLE:) Your work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____
f. Your emotional well-being	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____

27 P. Caregiver Assessments

Minnesota's Long Term Care Consultation Services Assessment Form (cont'd)

P.8 Is there anything that makes it difficult for you to provide care to (person's name)?

Yes (DESCRIBE) \_\_\_\_\_

No

Do you have any concerns about caring for (person), either about yourself, other family members or (person name) \_\_\_\_\_

RI

R2

**Assessor:**

P.9 List any factors that may limit caregiver:

	Yes		Yes
Job restricts caregiving	<input type="checkbox"/>	Caregiver has difficulty making appropriate decisions	<input type="checkbox"/>
Family responsibilities restrict caregiving	<input type="checkbox"/>	Caregiver financially dependent upon person	<input type="checkbox"/>
Limited knowledge to manage care	<input type="checkbox"/>	Caregiver may have mental health/substance abuse	<input type="checkbox"/>
Caregiver is physically impaired	<input type="checkbox"/>	Other (SPECIFY) _____	<input type="checkbox"/>
Person's needs are heavy physical burden for caregiver	<input type="checkbox"/>	None	<input type="checkbox"/>
Person's needs are heavy emotional burden for caregiver	<input type="checkbox"/>		
Caregiver's finances limit caregiving potential	<input type="checkbox"/>		

P.10 How would you rate your level of burden in caring for (NAME OF PERSON)?

None  Low  Medium  High

P.11 What caregiver services are you presently receiving? (e.g. respite, care planning, training, information, care coordination, coaching, etc.)

None  Other \_\_\_\_\_

P.12 What services or community support would help you, the caregiver, to keep providing care for (NAME OF PERSON) to help keep him/her living in the community?

\_\_\_\_\_  
 \_\_\_\_\_

P.13 Would you like to be contacted by a community organization that can give you more information and assistance with caregiving?

Yes  No

**Assessor:**

If the caregiver is presently receiving supportive services or answered "yes" to P.13, code 27-F in Section K of this form and in Section G on LTC SDoc (Services Plan)

**Comments On Caregiver/Community Support Plan Implications:**

82

Washington State's CARE Tool  
(1 page caregiver component)

CAREGIVER STATUS					
<b>CAREGIVER LIST</b>					
LAST NAME			FIRST NAME		
<b>CAREGIVER DETAIL</b>					
DO YOU LIVE WITH THE CLIENT? <input type="checkbox"/> Yes <input type="checkbox"/> No		IF NO, WHAT IS THE DISTANCE YOU LIVE FROM THE CLIENT? _____ Miles		HOW LONG HAVE YOU BEEN PROVIDING CARE? _____ Months _____ Years	
<b>SUPPORT SERVICES</b>					
ARE YOU CURRENTLY USING ANY CAREGIVER SUPPORT SERVICE(S)? <input type="checkbox"/> Yes <input type="checkbox"/> No		IF YES, WHAT AND HOW OFTEN <input type="checkbox"/> Caregiver Education/Conferences <input type="checkbox"/> One-on-one Training <input type="checkbox"/> Support Group <input type="checkbox"/> Counseling <input type="checkbox"/> Respite care services			
<b>STRESS BARRIERS</b>					
OVERALL HOW STRESSED DO YOU FEEL IN CARING FOR THE CLIENT? <input type="checkbox"/> Not Stressed <input type="checkbox"/> Somewhat Stressed <input type="checkbox"/> Very Stressed			ARE THERE ISSUES/ OBSTACLES THAT MAKE YOU AT RISK OF NOT BEING ABLE TO CONTINUE CAREGIVING? <input type="checkbox"/> Yes <input type="checkbox"/> No		
<b>BARRIERS TO CONTINUED CAREGIVING</b>					
<input type="checkbox"/> Decline in own emotional health		<input type="checkbox"/> Employment is negatively impacted		<input type="checkbox"/> Need (more) breaks from caregiving	
<input type="checkbox"/> Decline in own physical health		<input type="checkbox"/> Has other caregiving responsibility		<input type="checkbox"/> Relationship issues with client/family	
<input type="checkbox"/> Does not have necessary training/skills		<input type="checkbox"/> Level of caregiving is too difficult			
<b>Do you feel . . .</b>					
	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
that because of the time you spend with the client that you don't have enough time for yourself?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
stressed between caring for the client and trying to meet other responsibilities (work/family)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
angry when you are around the client?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
that the client currently reflects your relationship with family members or friends in a negative way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
strained when you are around the client?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
that your health has suffered because of your involvement with the client?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
that you don't have as much privacy as you would like because of the client?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
that your social life has suffered?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
that you lost control of your life since the client's illness?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
uncertain about what to do about the client?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
you should be doing more for the client?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
you could do a better job in caring for the client?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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# Assessment of Family Caregivers: An International Comparison Across Six Countries

Anne Montgomery, MS

## Abstract

An examination of the role that caregivers play in assessment processes in the long-term care systems of six countries (Australia, Canada, Germany, Japan, United Kingdom and the United States) shows a gradual movement towards taking the needs of family caregivers into account. But there remain large differences in the degree and manner in which caregivers are consulted about their own views, abilities and limitations. The aim of this paper is to provide an international comparison of how caregivers broadly fit into assessment schemes that are embedded in the long-term care systems of the six countries. Emerging common themes and recommendations for a caregiver assessment framework in the U.S. are explored.



## Introduction

The first half of the 21<sup>st</sup> Century presents policymakers in many countries with a complex challenge: to build programs adaptable to the changing needs and preferences of the many individuals with long-term care needs who wish to live with their families, and, concurrently, to create cost-effective and flexible forms of as-

sistance that aid their caregivers. Spouses, sons, daughters, other relatives and friends are the key source of voluntary support for millions of community-dwelling frail elders and persons with disabilities.

Spouses, sons, daughters, other relatives and friends are the key source of voluntary support for millions of community-dwelling frail elders and persons with disabilities.

## Purpose of Paper

The aim of this paper is to examine whether and how family caregivers are assessed in the context of publicly financed systems that provide home and community-based long-term care (LTC) services in six countries. All six—Australia, Canada, Germany, Japan, the United Kingdom and the United States—are members of the Organization for Economic Co-operation and Development (OECD). Suggestions for consideration by national and state policymakers, researchers, analysts and stakeholders are presented.

## Context of Family Caregiving in Six Countries

In five of the countries discussed (all except the U.S.), health services are organized and financed within the framework of a social insurance system of universal coverage. With respect to LTC coverage, however, the variance is considerably greater.

**Germany** and **Japan** have recently created (in 1995 and 2000) programs of social insurance coverage for LTC services that parallel long-established systems of acute health care in those countries (Cuellar & Weiner, 2000; Campbell & Ikegami, 2000).

In **Australia**, the de-institutionalization of aged care and disability services that took place during the mid-20<sup>th</sup> century led to gradual enactment of laws creating a range of community-based programs with various packages of services for different populations (Howe, 2000). The design of home and community-based services in **Canada** is principally within the purview of provinces and territories, with contributory financing from central and local governments, and co-payment policies that vary from area to area. A similar dynamic characterizes the **United Kingdom's** (UK) community care system (Huber, 2005). Finally, in the

**United States** (U.S.), most public financing of LTC comes through the means-tested Medicaid program, which has traditionally emphasized institutional services but has also seen recent rapid growth in home and community-based programs through administrative waivers (Kaiser Commission on Medicaid and the Uninsured, 2005). Among OECD countries, the U.S. has the highest percentage of private LTC expenditure as compared to public expenditure when calculated as a percentage of Gross Domestic Product (GDP) (Huber, 2005).

Policymakers in these very different societies are increasingly inclined to pay attention to programs that can help sustain the support that is already provided by family caregivers. While estimates of the number of caregivers who are available to provide

While estimates of the number of caregivers who are available to provide care at any given time vary widely from country to country (as do estimates of the economic value of their labor) it is evident that their voluntary support is indispensable to maintaining the integrity of publicly financed LTC systems.

care at any given time vary widely from country to country (as do estimates of the economic value of their labor) it is evident that their voluntary support is indispensable to maintaining the integrity of publicly financed LTC systems (Huber, 2005). Caregivers who assume responsibility for supporting individuals who are ill, frail and disabled make possible wider distribution of formal services and allow individuals without ready access to reliable informal support to receive more intensive services.

## Benefits of Caregiver Assessment

Documenting what assistance family caregivers are willing and able to provide can maximize allocation of scarce public resources (Weiner, 2003). Equally important, assessment provides an opportunity to identify caregivers' independent needs and to prevent "burnout" with targeted, cost-effective forms of assistance such as counseling, training in management of disease processes, specialized transportation, respite care and other related support services (Feinberg, Newman & Van Steenberg, 2002).

Just as a good medical history underlies accurate diagnosis and treatment, careful assessment of the dyad—both the caregiver and the individual who relies on a mix of informal and formal assistance to live at home—could strengthen and stabilize families while also providing a clearer roadmap for governments and providers aiming to deliver targeted and cost-effective services.

Moving from tacit acknowledgement to explicit recognition of what family caregivers do, why they do it and what they need also may help improve the quality of community-

based LTC services. As key partners in the provision of support, caregivers are well positioned to provide on-the-ground feedback about the quality and effectiveness of formal services.

In countries such as the UK and Australia, caregivers' input is viewed as an important part of the assessment process for planning community-based services for frail elders and persons with disabilities.<sup>11</sup> Still, providing caregivers with their own separate assessment appears to be less common, and the link between assessment and adequate follow-up services can be tenuous (Australian Institute of Health and Welfare, 2004).

By comparison, in the U.S. and Canada, family caregivers are still at the margins, not the middle, of government policy discussions that aim to enhance publicly financed LTC services. For example, in the U.S., caregivers' views are often not sought—and even less frequently recorded—in Medicaid assessment instruments that tend to focus on deficits in Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) (Feinberg et al., 2004).

<sup>11</sup> Note: In Australia and the UK, caregivers are known as "carers."

Expanding routine assessments to include caregivers has the potential to provide a more complete and accurate picture of which services, adaptive equipment and other forms of assistance are essential for both the person in need of care and for the family member giving care. Just as a good medical history underlies accurate diagnosis and treatment, careful assessment of the dyad—both the caregiver and the individual who relies on a mix of informal and formal assistance to live at home—could strengthen and stabilize families while also providing a clearer roadmap for governments and providers aiming to deliver targeted and cost-effective services.

## Australia: A Complex System with Increasing Caregiver Recognition

*Australia's LTC system is characterized by multiple federal and state programs that offer various "packages" of residential and home-based services for frail elders and persons with disabilities. The major assessment system gives caregivers an opportunity to be consulted and, in some circumstances, separately evaluated.*

Australia's system of LTC services is a mix of federal and state programs launched during the last 25 years. Arguably, the best known is the Home and Community Care Program (HACC), implemented in 1985 and jointly financed by the federal government and the states and territories (Department of Health & Ageing, 2002). HACC has no mandatory assessment requirement, principally due to an initial lack of consensus about whether the entities then being organized to conduct assessments—Aged Care Assessment Teams (ACATs)—were the best venue for assessing clients for community services and whether requirements for formal assessment could run counter to more ready access to community care as compared to nursing home care (A. Howe, personal communication, June 9, 2005).

HACC services include personal care, nursing care, meals, home maintenance, home modification, transport, counseling, support, information and advocacy, assessment, and care planning. The program identifies family caregivers as clients in their own right and offers a range of services to support them, such as in-home and center-based respite care (Aged & Community Services Australia, 2002). Assessment by HACC agencies frequently includes the caregiver where one is available, which is the case for about half of all HACC clients (A. Howe, personal communication, June 9, 2005).

A national, but not mandatory, framework for comprehensive assessment was developed within HACC in the late 1990's. According to this framework, "the purpose of a comprehensive assessment is to establish a consumer-focused approach to assess-

ment which encompasses client/family/carer participation in the assessment process and leads to individualized care solutions.... Separate client and carer assessments are undertaken where required or where the need is apparent. In addition, carers may be assessed in their own right without the person they care for needing to be assessed as

well.” (Department of Health & Ageing, n.d.). Many community care agencies are moving to incorporate the framework’s features into their assessment practice.

The purpose of a comprehensive assessment is to establish a consumer-focused approach to assessment which encompasses client/family/carer participation in the assessment process and leads to individualized care solutions.

Due to the diversity of assessment procedures within HACC and other newer community care programs with varying eligibility criteria, the feder-

al government is attempting to develop consensus with the states on a more uniform approach. Consistency in assessment practice across different agencies concerns researchers and federal government officials but, to date, no agreement exists in HACC on using a standardized assessment instrument for caregivers. The choice of a particular instrument is considered just one part of the overall assessment process (A. Howe, personal communication, June 9, 2005).

The most structured assessments—both for HACC and other programs offering residential and community care—are conducted by ACATs. Importantly, ACATs are set up to be independent of residential or community care providers. The Secretary of the Department of Health and Aging approves ACAT assessors as functionally independent, appointed delegates who are employed in the states’ health services sectors, often by a state public hospital (A. Howe, personal communication, July 18, 2005). This arrangement, in place since the mid-1980’s, reflects the structure of Australia’s health system, under which the federal government does not directly operate health and aged care services. Members of the ACAT come from different professional backgrounds, mostly nursing and social work.

ACATs conduct assessments for residential care in nursing homes and hostels (similar to assisted living facilities) and for Community Aged Care Packages (CACPs) that provide higher levels of home-based services, including case management. Provision of CACPs and residential care services is set according to ratios of places per 1,000 population aged 70 years and over. Means-testing for fees is applied according to standard policies only after care services have been recommended based on functioning. The means-test considers the client’s income and assets, with no contribution requirements for family members. For community services, co-payments are usually modest, and retirees and younger persons with disabilities on pension-only incomes are generally exempt (Department of Health & Ageing, 1999).

ACATs are directed to help older people live in the community and, in doing so, to consult with them and their caregivers during the assessment and care planning

process (Department of Health & Ageing, 1999). Unless a client disagrees, ACAT assessors generally speak with both members of the dyad about the client's condition and needs. In practice, assessors may choose among various instruments for assessing both clients and family caregivers, and these assessments serve as a guide for subsequent care planning by providers. Assessors frequently discuss problems that the caregiver may be having in relation to the caregiving role, but ACATs vary widely in how they conduct discussions and their ability to respond fully to all concerns, e.g., reports of marital tensions (A. Howe, personal communication, March 29, 2005).

If the ACAT recommendation is for residential care, the facility's director of care (usually a nurse) conducts a further assessment once the client is admitted. This evaluation uses a standard instrument, the Resident Classification Scale, to assess a person's functioning and care needs, set a level of care and determine the reimbursement rate in the residential case-mix payment system (Department of Health & Ageing, 1999).

For all types of care, ACAT assessors use the Aged Care Client Record (ACCR), an official document that notifies the federal government of the individual's eligibility for services. The ACCR requests very basic information about caregivers, including the relationship to the client and whether the caregiver is co-resident. It tries to distinguish assistance from formal services (such as meals, transportation and home care) from that received from family caregivers but does not record the amount of time caregivers spend in providing support. It asks about the use of residential and/or community-based respite care during the last year and whether respite has been recommended (Department of Health & Ageing & the Health Insurance Commission eBusiness pilot, 2005).

HACC providers collect information on client service use through a Minimum Data Set (MDS). The HACC MDS has been less successful in accurately recording all services directed to and used by family caregivers as clients in their own right since it captures only different forms of respite care. ACATs have their own MDS, which reports many similar items, including the presence of a family caregiver and types of services being used at the time of assessment and those recommended in the care plan. The ACAT MDS provides some indicators of how ACAT assessment can increase access to respite care. For example, a 2001-2002 comparison of services in Victoria found that use of in-home respite care at the time of assessment was 5 percent, but recommended for 12 percent; use of residential respite 7 percent, but recommended for 36 percent; and use of day center care, 9 percent, but recommended for 17 percent (A. Howe, personal communication, July 18, 2005).

In addition to ACATs, Community Health Centers, District Nursing Services and local governments are all commonly used as entry points for community services. They use various assessment procedures. In some—but not all—states, assessment procedures and care planning processes have been effectively consolidated and standardized across community services (Pierce & Nankervis, 1998).

In response to calls for consolidation and simplification of assessment processes and streamlining of access to community care services, the federal government undertook a review of community care in 2002. It led to a new strategy, released by the Minister for Aging in August 2004. Initiatives to implement the strategy's recommendations—including a call for “consistent eligibility criteria for community care programs” and “nationally consistent intake assessment for HACC services within the national framework that also encompasses other community care programs”—are now underway (Department of Health & Ageing, 2004).

## Canada: Provinces Have Major Role in Determining Assessment Policy for Community Services

*Canada's health and social services programs are mainly administered by the provinces, and assessment procedures do not yet recognize family caregivers as clients. Many home care workers are public employees or employees of agencies that contract with provincial social services or health agencies.*

Under the Canadian constitution, delivery of health care services is primarily a provincial or territorial responsibility. However, general federal legislation—most importantly the Canada Health Act—requires “free and universal access to insured health care” to be provided according to organizing principles in the areas of public administration, comprehensiveness, universality, accessibility and portability. An individual who resides in one province can receive services in another, and the province that delivers those services is reimbursed according to its own rates.

The Canada Health Act prohibits user fees and extra billing for services deemed to be “medically necessary”—including hospital, physician, nursing and rehabilitation services. In contrast, “extended health care services”—which include home care and residential care—are subject to charges at either partial or full private rates. Provinces may cover additional health services, such as assistive devices and prescription drugs; these are subject to payment policies set by each province. Home support services, which encompass personal care, do not fall under the Act's jurisdiction, and charges therefore vary significantly among the different jurisdictions (Madore, 2003).

According to a recent federal survey by Health Canada, mechanisms for administering, funding and delivering home care differ from province to province. For example, Prince Edward Island, the Northwest Territories and Yukon have departments of health and social services that are responsible only for home care,

while Newfoundland and New Brunswick have departments of health and community services that include home care among an array of services (Health Canada, 1999). In some jurisdictions, home care services have been devolved to local or regional health authorities; 149 regional health boards/authorities, district health boards and nonprofit corporations operate across Canada. In Ontario, 43 community care access centers delivered home care and in Quebec, 146 local community services centers (LCSCs) delivered these services. Recent mergers have created much larger Health and Social Service Centers that include several former LCSCs, public LTC facilities and nonteaching acute care hospitals in a specific geographical territory. A roundtable convened by Health Canada expressed concern that the current mix of nonprofit and for-profit providers and varying resources devoted to home care across the provinces means that “for the most part, care in the home is unsupervised” (Health Canada, 1999).

In 1999 the federal government agreed to provide provinces and territories with \$11.5 billion (Canadian dollars) in new funding over five years for health and social programs that include home care (Health Canada, 1999). In general, the federal government holds the power of setting the level of “transfer” payments for health and social services, since it collects taxes and redistributes funds to the provinces. Most often, however, the federal government’s power in health care is considered one of persuasion. In this role, the Ministry of Health has recently encouraged provinces to invest less in institutional services and spend more on home care (N. Guberman, personal communication, July 10, 2005).

In 2004, a new post, the Minister of State (Families and Caregivers), was created within Social Development Canada to raise the level of public awareness about the role of family caregivers in supporting frail elders and persons with disabilities. Minister Tony Ianno has undertaken a broad consultation with individual caregivers and caregiver organizations, with the goal of producing a report on findings and recommendations in 2005. The Ministry of Health is likely to review any policy recommendations since Health Canada is the federal department that considers home care and community care policy (J. Dempster, interview, April 5, 2005).

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In practice, provinces are free to devise different assessment procedures for persons found to be eligible for home and community services. In Ontario, under the Long-Term Care Act of 1994, community services include personal care, such as ADL assistance; provision of equipment; homemaking services that encompass IADLs such

as banking and preparing meals; professional services, such as nursing, social work and nutrition services; and respite, counseling, training and provision of information to caregivers. However, this Act does not designate caregivers as official “consumers” and they are generally not assessed (Canadian Legal Information Institute, 2005).

By comparison, Quebec’s home care policy of 2003 clearly presents caregivers as partners and potential clients of the system, and home care agencies, which are public, are charged with prioritizing specific services for caregivers. Quebec’s ministry of health and social services has named a committee to evaluate various caregiver assessment tools and propose a tool for adoption to complement the province’s multi-client assessment tool for people with various disabilities and illnesses. The committee has proposed that all caregivers be screened for risk, and that those scoring high should be assessed with an adapted version of the Caregivers’ Aspirations, Realities and Expectations (C.A.R.E.) Tool, developed by researchers at the University of Quebec and Mount Saint Vincent University (N. Guberman, personal communication, March 16 & July 10, 2005; J. Keefe, April 28, 2005). However, little assessment of caregivers has occurred to date because agencies received no funding to fulfill this policy mandate.

## Germany: Long-Term Care System with Cash Allowances

*Germany’s long-term care insurance program for frail elders and persons with disabilities features a standardized national assessment system. Care plans are drawn up by providers of institutional or home care services but not for individuals who choose the cash benefit only.*

A decade ago, Germany enacted legislation to finance and provide LTC services, billing the program as the “fifth pillar” of the country’s social insurance system. Employees and employers finance the LTC program at the level of 1.7 percent of salary. The program has a global cap, which simultaneously controls overall spending and affects eligibility criteria for formal services, cash allowances for families and provider payments. Automatic annual inflation factors are not built in (Cuellar & Weiner, 2000).

Although income is not taken into account for eligibility purposes, Germany’s program encourages and builds on the work of family caregivers. The program offers a cash allowance for families who wish to organize their own services, and the money comes with no real restrictions. If a family chooses to receive LTC benefits in cash—the value of which is slightly less than half the cost of formal home care services—the allowance is not taxed or subject to social security deductions. Families also may choose a mix of cash and formal services (Cuellar & Weiner, 2000). Services offered by home

care agencies focus mainly on ADL care and are not intended to meet all needs: for example, psychosocial care and housework are not covered. For beneficiaries who are more disabled, the LTC program offers nursing home care (Meyer, 2004).

Medically trained personnel employed by one of 17 agencies conduct all assessments. Assessors visit families in their homes and determine the level of care in accordance with national guidelines; their decisions are binding on the LTC funds that finance services. The guidelines focus on four main areas covering 15 activities: personal hygiene (such as toileting and bathing), eating, mobility (such as dressing, leaving home, moving around in home) and housekeeping (including IADLs such as grocery shopping, cooking, washing clothes and dishes). Three benefit levels are recognized: level one involves a need for assistance with at least two ADLs and some IADLs at least once a day and 90 minutes or more weekly; level two, a need for assistance with two or more ADLs and some IADLs three or more times a day and at least three hours weekly; and level three, generally round-the-clock care. A key criterion for the benefit-level decision is the amount of time a family caregiver needs to provide assistance with personal care, feeding, mobility and housework. A service need expected to last for at least six months is also required (Federal Ministry of Health & Social Security, 2004).

Importantly, the guidelines state that a caregiver for the person filing for LTC coverage should be present during the assessment if at all possible and that the assessor should document the caregiver's views about needed services. The assessor is not required to ask a caregiver for information about his/her own needs and health, but a caregiver who agrees to provide at least 14 hours per week of support is entitled to certain benefits, including automatic filing of claims for accidental insurance and state pension benefits. The amount of the pension contribution is tied to the beneficiary's assessed disability level and the amount of unpaid time provided by the caregiver each week. On average, one year of support raises a caregiver's monthly pension benefit between \$5.50 and \$20. In addition, recognized caregivers are eligible for up to four weeks of respite care each year (G. Langerhans, personal communication, May 25, 2005).

Assessors can recommend rehabilitation, home modifications and special technical aids but home care agencies and nursing homes develop the details of individual care plans. If the beneficiary chooses the cash benefit only, no care plan is considered necessary (G. Langerhans, personal communication, May 25, 2005). While family caregivers have access to periodic hands-on training courses run by the LTC funds, the popularity and effectiveness of these is unclear (Wilbers, 1999).

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Due to privacy concerns, families do not automatically receive a copy of the assessment, nor do ambulatory care providers, such as home care agencies. Only the LTC funds (or private LTC insurer if an individual has chosen to opt out of the public system and purchase privately) automatically receive a copy.

In 2003, many more LTC beneficiaries chose the cash benefit only (71%) than a combination of cash and services (15%) or services only (12%) (Meyer, 2004). The tendency to opt for cash-only benefits may reflect the LTC program requirement that families choosing nursing homes must contribute significantly toward living expenses (food and board). The LTC funds pay a flat monthly fee for nursing home care; residents must pay for at least 25 percent of monthly costs. The government encourages families to opt for caregiving and home care, asserting, “The main provider of long-term care has always been the family.... This is a good arrangement because most people who need long-term care want to live with their families and in familiar surroundings as long as they can. Hence, home care must be given priority over institutional care” (Federal Ministry of Health & Social Security, 2004).

The LTC assessment process, introduced in the 1990’s, was widely criticized as being biased in favor of older people with physical problems. Legislation enacted in April 2002 provides additional benefits for people with cognitive impairments, such as those with dementia, psychiatric illnesses or mental disabilities; an added monetary allowance of about \$600 annually for respite care is provided for family caregivers who support persons with cognitive impairment (Federal Ministry of Health & Social Security, 2004).

Evolving efforts to monitor quality reflect the German system’s clear-cut separation of “purchaser” and “provider.” Home care agencies under contract with 16 regional LTC fund associations are required to visit families who have chosen the cash benefit to check on the adequacy of care being delivered to the beneficiary and provide additional information and training for the caregiver if needed. The LTC fund associations are charged with monitoring providers and pay for the visits—semi-annual for care levels one and two and quarterly for care level three. Families may choose among approved agencies for these visits.

For nursing homes and home care agencies, assessors employed by one of 17 medical agencies administer a retrospective system of “quality checks.” The protocol for these checks includes unannounced visits and standardized questions for persons receiving care and/or family caregivers (G. Langerhans, personal communication, May 25, 2005).

## Japan: Standardized, Caregiver-Neutral Assessment Process for Long-Term Care

*Japan's long-term care system features a standardized national assessment protocol that classifies the needs of elderly individuals according to six functional levels. Its range of institutional and home-based services includes adult day care and respite care. Rather than building on and supplementing the work of family caregivers, Japan's system emphasizes the responsibility of the state to fund agreed-on services.*

The centerpiece of Japan's long-term care insurance (LTCI) program is a nationally standardized assessment system of 79 questions and an algorithm that classifies applicants into six levels of disability based on ADL deficits, use of medical services, behavioral problems and cognitive status (Campbell & Ikegami, 2000). It focuses on frail elders and younger disabled persons, 40-64, who have a qualifying "age-related disease," such as early-onset Alzheimer's, and deliberately excludes an individual's income and the availability of informal care. The LTCI national assessment includes no caregiver questions (N. Ikegami, personal communication, May 12, 2005).

Employees of the country's municipalities (usually public health nurses) or of independent agencies under contract gather the initial information on an applicant's condition and enter this information into the municipality's computers. Software classifies the applicant as meeting one of six disability levels or as ineligible. An "expert committee" composed of physicians, nurses and other providers appointed by the mayor has the authority to revise the level upward or downward based on a more detailed examination of the applicant's circumstances and an accompanying report from the attending physician. In 2003, the computer model was adjusted to add an indicator of dementia, which generally serves as a flag to the expert committee to consider raising the level (Tsutsui & Muramatsu, 2005).

The benefit amount is tied to the final assessed level of disability. Functioning like a voucher, it is a monetary cap within which a range of services can be designed and delivered each month, such as home help, rehabilitation, home modifications, wheelchair rental, respite care and adult day care. Monthly amounts range from about \$550 to \$3,400 (N. Ikegami, personal communication, July 9, 2005). The co-payment requirement for beneficiaries is 10%.

Care managers employed by providers develop detailed care plans. Although Ministry of Health, Labor & Welfare (MHLW) officials favored a standardized care planning process for LTCI implementation, provider associations resisted strongly. Ultimately government officials were forced to allow providers to use one of five instruments—the Resident Assessment Instrument for home care (RAI-HC) favored by

MHLW, and four others designed by provider associations representing visiting nurses, social workers, long-term care facilities and care workers (Ikegami & Nishiyama, 2003). In practice, most care plans are summaries of services to be delivered, and assessment forms are seldom filled in. Thus, the government has not been able to construct a unified database for evaluating quality or the reliance placed on the family.

In theory, care plans must primarily reflect the beneficiary's wishes, and secondarily the wishes of family members. The actual responsibility for accomplishing these goals falls to the care manager, who draws up the plan. The care plan must specify the number of hours of services on a calendar-month basis. If beneficiaries don't like their care manager, they may choose another, although this option is not viable in rural areas with few agencies (N. Ikegami, personal communication, May 12, 2005).

LTCI's caregiver-neutral national assessment system was designed in response to successful arguments by Japanese feminists that the system should relieve women—and most particularly daughters-in-law and daughters—from historical and cultural expectations that held them responsible for providing support to ailing elders. Even with the infusion of new services, recent research suggests that families still struggle with unmet needs. For example, the national assessment instrument is believed to underestimate the impact of behavior problems associated with Alzheimer's disease (Arai, Zarit, Kumamoto & Takeda, 2003). Families struggling with Alzheimer's disease receive fewer services than families coping with vascular-type dementia.

Japan's LTCI system, which became effective in 2000, is financed with premiums paid by individuals 40 and older (50%), and with general revenues (50%). LTCI covers services that were once within the purviews of the social welfare and health care systems (home help, day care, nursing homes, rental of equipment, home modification, visiting nurses, physical therapy, intermediate care facilities) (Campbell & Ikegami, 2000). To contain greater-than-expected increases in costs, fees were lowered in 2003, and "hotel costs" will be charged for institutional care starting in October 2005 (N. Ikegami, personal communication, July 9, 2005).

## United Kingdom: Caregiver Assessment Is a Right, and the Key to Community Care

*The UK stands out for providing family caregivers with a strong statutory right to receive an assessment when an adult applying for community services is being assessed, as well as the right to a separate, independent assessment. The percentage of local authorities that provide information to caregivers has improved considerably and respite care is reaching many caregivers, but access to other kinds of services is still limited.*

A seminal 1995 law, the Carers (Recognition and Services) Act, first provided caregivers with a statutory right to request assessment when a frail elder or adult with disabilities is assessed for community services. Legislation enacted during the late 1990's devolved authority for health and community care services to separate elected legislatures, but laws enacted in England and Wales in 2000 and in Scotland and Northern Ireland in 2002 gave caregivers the right to an independent separate assessment. Across the UK, community care encompasses residential long-term care and home-based services, which local authorities administer with capped funding from central government. Community care services are subject to means-tested co-payments that vary substantially across local authorities (Montgomery & Feinberg, 2003).

The 1995 Act specifically required local authorities to assess the caregiver's ability to provide support to a person with disabilities (adult or child) before deciding which services would be provided. To trigger their right to be evaluated, caregivers must affirmatively request an assessment and be judged as providing "a substantial amount of care on a regular basis" (not specifically tied to a minimum number of hours). Studies found that the varying assessment processes created by local authorities produced significantly different patterns of services for similarly disabled adults living in different areas—and only scant services for caregivers (Carers National Association, 1997). In response to rising concerns about equity, the Department of Health (DoH) in England published mandatory guidance in 2002; it directs local authorities to take a more uniform approach to assessment of need and determination of service eligibility. The "Fair Access to Care" guidance specifies four bands of eligibility criteria—critical risk, substantial risk, moderate risk and low risk—and calls for attention to services that can maximize an applicant's independence and autonomy.

Laws enacted in England and Wales in 2000 and in Scotland and Northern Ireland in 2002 gave caregivers the right to an independent separate assessment.

The guidance asserts, “For many individuals the help and support of family members or other caregivers is essential to them remaining independent. Often caregivers should, and need to, be involved in the assessments and subsequent decisions about the help that is provided to the individual.” Without explaining how caregiver input is to be solicited, the guidance requires that care plans document “contributions which caregivers and others are willing and able to make.” It also notes that caregivers have a right to be separately assessed for their own needs and the “sustainability of the caring role” under the 2000 Act (Department of Health, 2002).

DoH developed separate guidance on a single assessment process in the March 2001 “National Service Framework for Older People.” The assessment domains include problems with services from the perspective of the older person; a history of medical problems and treatment; a description of the person’s abilities and limitations in self-care; an account of sensory impairments; a description of any cognitive impairment; notation of the person’s social relationships and caregiving arrangements; a listing of possible safety hazards and abuse and neglect problems; and a description of the individual’s home, finances and access to local health facilities and services. The DoH guidance has now been implemented across England (Department of Health, 2002).

The Carers (Equal Opportunities) Act of 2004 expands the right of caregivers in England and Wales. During the assessment, local authorities are to take into account a caregiver’s other major life activities—education, employment and leisure. To date, the leading group in the UK representing caregivers, Carers UK, has not advocated that local authorities use a standardized assessment instrument, but has frequently urged that more services be directed to caregivers (Carers UK, n.d.).

A recent survey by the Audit Commission of caregivers in six areas of England concluded that local authorities have made progress during the last decade in identifying caregivers, in providing information to them about where to go for assistance and providing referrals on applying for benefits beyond community care, such as cash allowances. Nearly two-thirds of surveyed caregivers said they had received respite care during the previous year. A majority had been involved in the assessment of the person they were supporting but relatively few had been separately assessed. Involvement of caregivers in planning services for a person being discharged from a hospital (which is a joint responsibility of local authorities and the National Health Service) was found to be spotty (Audit Commission, 2004).

Scotland’s approach has taken a somewhat different course. Its government opted to take up the UK-wide Royal Commission on Long Term Care’s 1999 recommendation that the government should provide “free” personal care, not subject to means-testing (Royal Commission on Long Term Care, 1999). The only “free” services in England are a narrower range of discrete services defined as “nursing care” within the jurisdiction of the National Health Service (NHS) (Montgomery, 2002).

As part of the development of a “Single Shared Assessment” protocol, the Scottish government is implementing the Resource Use Measure (RUM). This instrument places individuals applying for community care into nine categories using 12 questions, each of which has numerous components. Explanatory material provides guidance on how the instrument can be most effectively used to make services decisions. Although personal-care questions may flag a possible caregiver contribution (e.g., “requires prompting, guidance, supervision or encouragement” and “cannot do without assistance from others”), no follow-up questions address what help the caregiver may need or ask for information on the impact of providing such assistance. The broader protocol instructs agencies providing services to draw up “a common set of values” that include “recognizing and supporting the contribution of family and other [carers] and ensuring their contribution and needs are considered either as part of the assessment of the cared for person, or as a separate carer’s assessment” (Scottish Executive, 2005).

## United States: Long-Term Care Programs Rarely Assess Caregivers’ Own Needs for Support

*The U.S. has a decentralized LTC system that features a mix of public and private funding. Assessment and care planning processes now vary from state to state under Medicaid and the Older Americans Act’s National Family Caregiver Support Program (NFCSP). State Medicaid programs frequently take into account the availability of informal support in making services determinations but generally do not offer caregivers an opportunity to be assessed.*

The largest LTC program in the U.S.—Medicaid—now accounts for 43 percent of all long-term care spending and finances close to two-thirds of nursing home care (Kaiser Commission on Medicaid and the Uninsured, 2005). Increasingly, there are calls for federal legislative action to change Medicaid significantly, including LTC services, with an eye toward cost containment. One proposal would tighten eligibility for individuals with a history of giving away money and resources to children, or otherwise transferring assets, prior to applying for LTC services (National Governors Association, 2005).

Family Caregiver Alliance’s National Center on Caregiving conducted the most comprehensive study of caregiver programs and assessment procedures in 2004, with funding from the U.S. Administration on Aging. The 50-state survey, which included state-funded home and community-based services (HCBS) programs, Aged/Disabled Medicaid waiver programs and the NFCSP, found that only five

states have uniform HCBS assessment procedures with a family caregiving component. The NFCSP has no mandate for systematic assessment of caregivers and no uniform recommended assessment instrument, but a few state-funded caregiver support programs, notably California, have standardized assessment processes for caregivers (Feinberg et al., 2004).

Federal law requires states to assess Medicaid applicants to determine whether they meet “level of care” criteria, and HCBS waiver eligibility criteria must be the same as nursing home eligibility criteria. Within broad parameters, states are permitted to

Only five states have uniform HCBS assessment procedures with a family caregiving component.

employ different methods of determining an applicant’s level of care: some use an instrument that generates a score, while others require a minimum number of impairments or needs and still others rely on definitions and guidelines. A 1996 AARP survey of 42 states found the availability of family caregiving support to be an item considered in 13

states’ HCBS waiver programs. However, noting the availability of informal support does not constitute an assessment of caregivers’ needs (O’Keefe, 1996).

States’ care planning processes also vary. Another 1996 AARP study of four states found that care plans “attempt to address unmet needs by building upon existing informal care.” However, decisions made about services for a beneficiary are not linked clearly to a caregiver’s needs, limitations and abilities to provide appropriate support (Kassner & Martin, 1996).

Medicaid’s “Cash and Counseling” program, initially funded in 1996-1997 by the Robert Wood Johnson Foundation and the U.S. Department of Health and Human Services (HHS), may hold the promise of a more inclusive approach to assessing needs. An individualized budget is agreed to by Medicaid and the beneficiary in consultation with involved family members; the monthly monetary amount is based on the cost of services outlined in the care plan (minus a standardized discount). Once negotiated, the budget is largely under the beneficiary’s control. A hallmark of the Cash and Counseling program is that the beneficiary may hire a personal care assistant of his or her choice—often a family caregiver (Mahoney, 2005). The first phase of the Cash and Counseling program enrolled beneficiaries in three states—Arkansas, Florida and New Jersey—and the program has been expanded to 12 additional states, now at various stages of enrolling beneficiaries. To ensure fiscal integrity, the program requires all states to provide beneficiaries with administrative support for payment of taxes and related issues. Family caregivers in the program are entitled to Social Security, a concept that bears some resemblance to the public pension credits accumulated by caregivers in Germany and the UK who are out of the workforce.

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## Conclusions

Several conclusions can be drawn from this international comparison of caregiver assessment policy and practice. In Germany, Australia and the UK, caregivers are considered to be critical to the functioning of the formal LTC system. This acknowledgement has not occurred overnight: it is the result of years of effort by individuals and organizations representing caregivers, and by groups representing persons with chronic diseases and disabilities that are sympathetic to caregivers' interests. The role of research has been key in providing detailed profiles of who caregivers are, how they contribute to supporting homebound persons and the often-minimal services caregivers have received from formal LTC systems. Such evidence has helped to persuade policymakers that assistance for caregivers should be a more prominent political priority. Programs of targeted services— notably respite care—are the tangible result. As caregivers have become a visible constituency, questions that begin to identify and clarify caregivers' needs have been introduced into some community care assessment protocols.

In the UK, this acceptance has taken the form of a concrete statutory right to assessment for caregivers—giving them standing to voice concerns about the design and delivery of community care services that local authorities administer. Caregivers can exercise their right to assessment in conjunction with the assessment of a frail elder or person with disabilities, or request to have a separate, stand-alone assessment. Also, caregivers in England and Wales can be assessed in the broader context of competing priorities and demands (e.g., education and employment).

In Australia, the national assessment guidelines call for taking the needs of caregivers into account when making recommendations for services across a wide range of aged care programs. In addition, caregivers have been considered clients in their own right in the major federal/state HACC program since its inception, with HACC guidelines calling for caregivers to be “closely involved” in assessments of frail elders and younger people with disabilities. Caregivers' input is considered critical to the assessment and planning of services in the country's more recently introduced CACP program, which targets intensive packages of services to individuals with complex needs.

Germany's national LTC program directly integrates family caregivers into the assessment process of frail elders and persons with disabilities. Caregivers are identified and evaluated for their eligibility for subsidized contributions made on their behalf by the LTC program to the state pension program; respite care; training in practical skills; and publicly financed home modifications. Together with the family member needing care, German caregivers can choose to receive a cash allowance in lieu of formal home care services, or a pro-rated cash allowance combined with formal home care services.

In the U.S. and Canada, caregivers have not yet been integrated into assessment procedures for programs that serve frail elders and individuals with disabilities. In the U.S., the presence of a family caregiver is often noted during assessments of

In the U.S. and Canada, caregivers have not yet been integrated into assessment procedures for programs that serve frail elders and individuals with disabilities.

Medicaid-eligible individuals, but no follow-up examines the caregiver's own limitations, abilities and desires for support. In both countries, consensus on a caregiver assessment instrument—or guiding principles for how caregiver assess-

ment should be incorporated into broader LTC assessment protocols—has not yet emerged. Basic domains for assessing caregivers have been explored by researchers in some depth, however, and standardized instruments are being tested and/or used in several states and provinces.

In Japan's comprehensive long-term care insurance system, care plans developed by providers and beneficiaries are not standardized. Moreover, at the initial stage of assessment, older persons are not asked about either their income or the availability of any caregiver support; thus, the government has scant information about the status of beneficiaries in relation to family caregiver support. Japan's earlier history—expecting women to care for parents and/or parents-in-law—shaped political discussions during the 1990's. The result is an effectively caregiver-neutral program, in which it may be difficult to develop a consensus caregiver assessment instrument or process.

The World Health Organization's 2003 compendium on key policy issues in long-term care argues that the central mission of any high-quality system is “to ensure that an individual who is not fully capable of long-term self-care can maintain the best possible quality of life, with the greatest possible degree of independence, autonomy, participation, personal fulfillment and human dignity.” Fundamental to achieving this goal, the report notes, is an assessment that includes “functional abilities across a comprehensive series of dimensions” such as ADL, IADL and cognitive measures, which are used to track health and quality outcomes. The report also urges that for those persons living with their families, “as the bulk of LTC is provided by informal caregivers and dependent upon their health and well-being, caregivers' needs must also be assessed in order to plan resource allocation” (Larizgoiti, 2003).

The time may be right for an alliance of organizations with expertise in caregiving to take up that challenge, and to approach policymakers with a proposal to develop a caregiver assessment framework to achieve this important goal.

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## Recommendations for Developing a Caregiver Assessment Framework

- ◆ A small group of “best practice” caregiver assessment instruments could be the starting point for discussions about how a consensus instrument could be constructed for use in a pilot demonstration. In these discussions, LTC and caregiver experts, HHS and a few state officials would clarify:
  1. How to record essential information about caregivers to identify their role in providing care and their possible need for independent support services;
  2. The potential to generate data on frail elders, individuals with disabilities and their caregivers for use in quality improvement initiatives; and
  3. Strategies for encouraging integration of caregiver assessment into existing assessment processes for federal and state-administered LTC home and community-based programs more broadly.
- ◆ Parallel discussions with government officials could focus on a more comprehensive instrument for caregiver assessment for use in programs targeted to reach caregivers, such as the NFCSP and state programs focusing on respite care, counseling and family support, as well as for use by others, such as researchers.
- ◆ For health care providers, a screening tool could be developed to identify caregivers at risk for (or experiencing) depression, fatigue and other conditions associated with stress and physical strain that warrant medical attention.
- ◆ Researchers could take up the question of integrating assessment information from home and community-based LTC programs into a unified national database to evaluate the quality and effectiveness of home and community-based services, their cost, and client and caregiver satisfaction rates.
- ◆ Researchers could also seek funding for evaluations of programs that offer a discrete range of targeted services within flexible federal parameters, such as the NFCSP, with the aim of clarifying caregivers’ views about which services, delivered in which ways, are most useful. Such evaluations would provide valuable information about the di-

verse situations of caregivers and the people they support. Ultimately, this type of information would inform and improve current assessment instruments and processes.

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## References

- Aged and Community Services Australia (2002). *Fact Sheet 3 - Community Care*. Retrieved July 24, 2005, from: [http://www.agedcare.org.au/factsheets/factsheet3\\_communitycare.htm](http://www.agedcare.org.au/factsheets/factsheet3_communitycare.htm)
- Arai, Y., Zarit, S., Kumamoto, K., & Takeda, A. (2003). Are there inequities in the assessment of dementia under Japan's LTC insurance system? *International Journal of Geriatric Psychiatry*, *18*, 346-352.
- Audit Commission (2004). *Support for Carers of Older People*. London: Belmont Press.
- Australian Institute of Health and Welfare (2004). *Carers in Australia: Assisting Frail Older People and People with a Disability*. Canberra, Australia: Author.
- Campbell, J. & Ikegami, N (2000). Long-term care insurance comes to Japan, *Health Affairs*, *19* (3), 26-39.
- Canadian Legal Information Institute (2005). *Text of Long-Term Care Act, 1994*. Retrieved on June 24, 2005, from: <http://www.canlii.org/on/laws/sta/1994c.26/20050511/whole.html>
- Carers (Equal Opportunities) Act 2004. Available at: <http://www.carersuk.org/Policyandpractice/CarersEqualOpportunitiesAct>
- Carers National Association (1997). *Still Battling: The Carers Act One Year On*. London: Author.
- Carers UK. (n.d.) *Carers Assessment Guide*. Available at: <http://www.carersuk.org/Information/Helpwithcaring/Carersassessmentguide>

- Cuellar, A. & Wiener, J. (2000). Can social insurance for long-term care work? The experience of Germany. *Health Affairs*, 19 (3), 3-25.
- Department of Health (2002). *Guidance on the Single Assessment Process for Older People*. Available at: <http://www.doh.gov/publications/coimb.html>
- Department of Health and Ageing & the Health Insurance Commission eBusiness Pilot (2005). *Aged Care Client Record*. Canberra, Australia: Author.
- Department of Health and Ageing (2004). *A New Strategy for Community Care—The Way Forward*. Canberra, Australia: Author.
- Department of Health and Ageing (2002). *A Summary of the National Program Guidelines for the Home and Community Care Program 2002*. Canberra, Australia: Author.
- Department of Health and Ageing (1999). *Aged Care Assessment and Approval Guidelines*. Canberra, Australia: Author.
- Department of Health and Ageing (n.d.). *National Framework for Comprehensive Assessment in the HACC Program*. Canberra, Australia: Author.
- Federal Ministry of Health and Social Security (2004). *Long-Term Care Insurance* (English translation). Retrieved May 5, 2005, from: <http://www.bmgs.bund.de/eng/gra/long/4293.php>
- Feinberg, L., Newman, S., Gray, L., Kolb, K., & Fox-Grage, W. (2004). *The State of the States in Family Caregiver Support: A 50-State Study*. San Francisco, CA: Family Caregiver Alliance.
- Feinberg, L., Newman, S., & Van Steenberg, C. (2002). *Family Caregiver Support: Policies, Perceptions and Practices in 10 States Since Passage of the National Family Caregiver Support Program*. San Francisco, CA: Family Caregiver Alliance.
- Health Canada (1999). *Provincial and Territorial Home Care Programs: A Synthesis for Canada*. Ottawa, Canada: Author.
- Health Canada. (1999). *Report on the National Roundtable on Home and Community Care*. Retrieved Nov. 16, 2004, from: <http://www.bc-sc.gc.ca/homecare/english/rt3.html>
- Health Canada. (1999). *Home Care in Canada 1999: An Overview*. Retrieved May 31, 2005, from: <http://www.bc-sc.gc.ca/homecare/english/profil.html>
- Howe, A. (2000). Rearranging the compartments: The financing and delivery of care for Australia's elderly. *Health Affairs*, 19 (3), 57-71.
- Huber, M. (2005). *Ensuring Quality Long-Term Care for Older People* (Policy Brief). Paris: Organization for Economic Co-Operation and Development.
- Ikegami, N. & Nishiyama, M. (2003). *Muddling Through LTC Policy: The Japanese Government's Approach to the Introduction and Dissemination of Resident Assessment Instruments*. New York: Milbank Memorial Fund.
- Kaiser Commission on Medicaid and the Uninsured (2005). *The Medicaid Program at a Glance* (Fact Sheet). Washington, DC: Author.

- Kassner, E. & Martin, J. (1996). *Decisions, Decisions: Service Allocation in Home and Community-Based Long-Term Care Programs. A Four-State Analysis*. Washington, DC: AARP Public Policy Institute.
- Larizgoiti, I. (2003). Approaches to Evaluating LTC systems. In J. Brodsky, J. Habib, & M. Hirschfeld, *Key Policy Issues in Long-Term Care* (226-242). Geneva, Switzerland: World Health Organization.
- Madore, O. (2003). *The Canada Health Act: Overview and Options*. Ottawa, Canada: Library of Parliament, Parliamentary Information and Research Service Economics Division.
- Mahoney, K. (2005). *Cash and Counseling Demonstration Overview*. Prepared for Alliance for Health Reform congressional briefing, July 29, 2005, Washington, D.C. Available at: <http://www.allhealth.org>
- Meyer, M. (2004). *Services for Supporting Family Carers of Elderly People in Europe: Characteristics, Coverage and Usage – EUROFAMCARE – National Background Report for Germany*. Hamburg, Germany: EUROFAMCARE.
- Montgomery, A. (2002). *With Respect to Carers: A Comparison of Their Role in the Evolution of Long-Term Care Policies in the UK and the US* (Final Report). Paper presented at June 2002 seminar of Atlantic Public Policy Fellows, sponsored by the British Council and the Foreign and Commonwealth Office, London.
- Montgomery, A. & Feinberg, L. (2003). *The Road to Recognition: International Review of Public Policies to Support Family and Informal Caregiving* (Issue Brief). San Francisco, CA: Family Caregiver Alliance.
- National Governors Association (2005). *Medicaid Reform: A Preliminary Report*. Washington, DC: Author.
- O’Keefe, J. (1996). *Determining the Need for Long-Term Care Services: An Analysis of Health and Functional Eligibility Criteria in Medicaid Home and Community-Based Waiver Programs*. Washington, DC: AARP Public Policy Institute.
- Pierce, G. & Nankervis, J. (1998). *Putting Carers in the Picture: Improving the Focus on Carer Needs in Aged Care Assessment*. Melbourne, Australia: Carers Association Victoria.
- Royal Commission on Long Term Care (1999). *With Respect to Old Age: Long-Term Care– Rights and Responsibilities*. London: The Stationary Office.
- Scottish Executive, Health Department, Directorate of Service Policy and Planning (2005). *Single Shared Assessment – Indicator of Relative Need Operational Guidance Resource Pack*. Edinburgh, UK: Author.
- The Community Care (Delayed Discharges etc.) Act 2003. Available at: <http://www.dh.gov.uk>
- Tsutsui, T. & Muramatsu, N. (2005). Care-needs certification in the long-term care insurance system of Japan. *International Health Affairs*, 53, 522-527.
- Weiner, J. (2003). The role of informal support in long-term care. In J. Brodsky, J. Habib, & M. Hirschfeld, *Key Policy Issues in Long-Term Care* (3-24). Geneva, Switzerland: World Health Organization.

Wilbers, J. (1999). Long-term care insurance in Germany, International Longevity Center. Retrieved April 28, 2005, from: [http://www.iclusa.org/\\_lib/pdf/wilbers/pdf](http://www.iclusa.org/_lib/pdf/wilbers/pdf)

## Informant Interviews and Personal Communication

Jeannie Dempster, Senior Policy Advisor to Minister Tony Ianno, Social Development Canada, April 5, 2005.

Nancy Guberman, University of Quebec, Montreal, Canada, March 16 & July 10, 2005.

Anna Howe, past President of the Australian Association of Gerontology, March 29, June 9, June 18 & July 18, 2005.

Naoki Ikegami, Department of Health Policy and Management, Keio University School of Medicine, Tokyo, Japan, May 12 & July 9, 2005.

Janice Keefe, Mount Saint Vincent University, April 28, 2005.

Gabriele Langerhans, Desk Officer, Federal Ministry of Health and Social Security, Department of Long-Term Care Insurance, Bonn, Germany, May 25, 2005.

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